

From the DEPARTMENT OF CLINICAL SCIENCE AND
EDUCATION, SÖDERSJUKHUSET
Karolinska Institutet, Stockholm, Sweden

**PATIENTS WITH CHRONIC PAIN -
QUANTITATIVE AND QUALITATIVE
STUDIES OF TREATMENT OR
REHABILITATION AT A PAIN CLINIC**

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**Karolinska
Institutet**

Stockholm 2016

Cover picture: Naomi Lawrence, München, Germany

Poem: Hermann Hesse, Sämtliche Werke. Herausgegeben von Volker Michels. Band 10:

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Published by Karolinska Institutet.

Printed by Eprint AB

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ISBN 978-91-7676-396-4

Patients with chronic pain – quantitative and qualitative studies of treatment or rehabilitation at a pain clinic

THESIS FOR DOCTORAL DEGREE (Ph.D.)

To be publicly defended at Aulan Södersjukhuset, Stockholm

Friday 28 October 2016, 1.00 pm.

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Schmerz

Schmerz ist ein Meister, der uns klein macht,
Ein Feuer, das uns ärmer brennt,
Das uns vom eigenen Leben trennt,
Das uns umlodert und allein macht.

Weisheit und Liebe werden klein,
Trost wird und Hoffnung dünn und flüchtig;
Schmerz liebt uns wild und eifersüchtig,
Wir schmelzen hin und werden Sein.

Es krümmt die irdne Form, das Ich,
Und weht und sträubt sich in den Flammen.
Dann sinkt sie still in Staub zusammen
Und überläßt dem Meister sich.

Hermann Hesse

ABSTRACT

Background and aim: Chronic pain is a major problem, often with comorbidity of insomnia, mental disorders and limitations in function, activity and participation, all leading to poor quality of life. Patients describe their pain as unpredictable and ‘invisible’ thus influencing being and communication. Patients with chronic pain are treated in primary care, pain clinics and rehabilitation units. Pain-clinic patients represent a wide range of diagnoses and knowledge of these settings is limited. The overall aim of the work presented in this thesis was to explore aspects of living with chronic pain among patients attending a pain clinic.

Methods and results: Three studies resulting in four papers were performed at a pain clinic where patient-adapted treatment alternatives included conventional, mainly pharmacological, pain treatment (CPT) and a team-based multimodal rehabilitation programme (MMR).

In **Study I**, interviews with 14 informants (13 female, age 23-77) who had participated in MMR one year earlier were analysed using content analysis. The core theme “*Change is possible*” and the themes “*A life ruled by pain*” (the situation before rehabilitation), “*The penny’s dropped*” (experience during rehabilitation) and “*Live a life, not only survive*” (the situation at the time of the interviews) emerged from the data. The process describes how the informants could integrate earlier disabling symptoms into a well-functioning lifestyle (Paper I).

Study II was a longitudinal, observational study of patients assessed and treated. Patient-reported outcome measures (PROM) of health-related quality of life (EQ-5D), pain (VAS), anxiety and depression (HADS), insomnia (ISI), pain related disability (PDI), kinesiophobia (TSK) and sense of coherence (SOC) were collected at the first visit and one year later. Data were analysed according to the treatment alternatives: MMR-group (n= 42) (Paper II) and CPT-group (n=271) as well as patients assessed and referred (AO-group, n=47) (Paper III). The baseline showed substantial problems in PROM with the worst state in the MMR-group. Significant improvements ($p < 0.05$) were found in the follow-up of both treatment groups in EQ-5D, ISI, PDI and TSK in the MMR-group. The CPT-group improved also in VAS, while the AO-group did not change.

Study III: In this qualitative study 13 women with painful endometriosis, treated with CPT, were included. Sixteen interviews were analysed according to grounded theory. The theory as developed describes the experience of endometriosis and its treatment in the core category. “Surviving painful endometriosis, struggle for coherence”, formed from the categories “Woman with painful endometriosis”, “Dependence” and “A ruined life”.

Conclusions: The analysis of interviews and questionnaires of patients with chronic pain at a pain clinic showed congruent findings: complex suffering, with significant influence of the pain condition on living and health. In the follow-up of minor or comprehensive interventions, improvement was found in several outcomes and patients described a change to a well-functioning life. However, ongoing problems remained, pointing to the chronicity of the condition. To live a good life with chronic pain requires the sufferer to understand her or his situation, to use functional coping strategies and to find support in significant others and health care, thus integrating the chronic condition.

LIST OF SCIENTIFIC PAPERS

- I. Hållstam, A., Stålnacke, BM., Svensén, C., Löfgren, M. (2015). "Change is possible": Patients' experience of a multimodal chronic pain rehabilitation programme.
Journal of Rehabilitation Medicine, 47: 242-248.
- II. Hållstam, A., Löfgren, M., Svensén, C., Stålnacke, BM. (2016). Patients with chronic pain: One-year follow-up of a multimodal rehabilitation programme at a pain clinic.
Scandinavian Journal of Pain, 10: 36-42.
- III. Hållstam, A., Löfgren, M., Benson, L., Svensén, C., Stålnacke, BM.
Assessment and treatment at a pain clinic: One- year follow-up of patients with chronic pain.
Scandinavian Journal of Pain, Epub ahead of print 9-Sep-2016
doi: 10.1016/j.sjpain.2016.08.004
- IV. Hållstam, A., Stålnacke, BM., Svensén, C., Löfgren, M.
"Tears included" – women's experience of painful endometriosis and its treatment.
Manuscript

CONTENTS

1	Introduction	1
2	Background.....	3
2.1	Pain	3
2.1.1	Chronic pain	3
2.1.2	The complexity of chronic pain.....	4
2.1.3	The patient's experience of chronic pain.....	7
2.2	Treatment of chronic pain	8
2.2.1	Development of health care for pain	8
2.2.2	Conventional treatment at pain clinics	8
2.2.3	Multimodal rehabilitation – MMR	9
2.2.4	Treatment outcome.....	9
2.3	The salutogenetic model and the sense of coherence.....	10
3	Ethical Considerations.....	13
4	Aims.....	14
4.1	Specific aims.....	14
5	Methods	15
5.1	Subjects and context	15
5.2	Data collection	16
5.2.1	Inclusion	16
5.2.2	Interviews	17
5.2.3	Patient-reported outcome measures.....	18
5.3	Data analysis.....	21
5.2.4	Content Analysis (Paper I).....	21
5.2.5	Grounded theory (Paper III).....	22
5.2.6	Statistics.....	23
6	Results.....	25
6.1	“Change is possible”: patients' experience of a multimodal chronic pain rehabilitation programme (Paper I).....	25
6.2	Patients with chronic pain: one-year follow-up of patients at a pain clinic (Papers II and III)	27
6.2.1	Baseline assessment	27
6.2.2	Changes over time.....	30
6.2.3	Associations.....	31
6.3	“Tears included” – women's experience of painful endometriosis and its treatment (Paper IV)	33
7	Discussion.....	37
7.1	General discussion.....	37
7.1.1	The burden of chronic pain	37
7.1.2	Assessment at the pain clinic	38
7.1.3	The situation at follow-up	39
7.1.4	The significance of health-care professionals	42

7.2	Methodological considerations	43
8	Conclusions	46
9	Implications	47
10	Future research	47
11	Svensk sammanfattning.....	48
12	Acknowledgements	50
13	References	53

ABBREVIATIONS

ACT	Acceptance and commitment therapy
AO	Assessment only
CBT	Cognitive behavioural therapy
CI	Confidence interval
CPT	Conventional pain treatment
EQ-5D	EuroQol Group trademark for a standardized instrument for use as a measure for health outcome
HADS	Hospital Anxiety and Depression Scale
HRQoL	Health Related Quality of Life
ISI	Insomnia Severity Index
IASP	International Association for the Study of Pain
MMR	Multimodal rehabilitation
NPS	Number of pain sites
OR	Odds ratio
PDI	Pain Disability Index
PROM	Patient-reported outcome measures
QoL	Quality of life
SOC	Sense of coherence
SQRP	Swedish Quality Registry for Pain Rehabilitation
SBU	Swedish Council on Technology Assessment in Health Care
TENS	Transcutaneous electrical nerve stimulation
TSK	Tampa Scale of Kinesiophobia
VAS	Visual analogue rating scale
WHO	World Health Organization

1 INTRODUCTION

During my many years as a nurse at the pain clinic at Södersjukhuset, the suffering of patients with chronic pain touched me and raised questions. Did our treatment help the patients, did they really get better? For some patients the pain induced major suffering and disability and despite great efforts, the outcome was of limited usefulness. For others, minor interventions seemed to have great influence on their pain and ability to live. When I got familiar with the salutogenetic theory of Aaron Antonovsky I started to wonder whether patients' sense of coherence could be a factor of importance to explain these differences.

In the early 2010s our pain clinic enlarged its treatment alternatives due to an increased understanding of chronic pain as a biopsychosocial problem and the need of interventions supplementing the goal of pain relief. The new paradigm and treatment possibility fit my understanding of holistic nursing. When implementing the multimodal rehabilitation programme there was a need for evaluation. A combination of quantitative and qualitative methods seemed necessary for studying the patient's view of the utility of treatments. When I found supervisors, and people who believed in my research ideas and in me, the doctoral project could start.

I hope this thesis gives some answers, but certainly also raises more questions about patients with chronic pain: that is what research is for! However, I hope this work can increase our knowledge and understanding of the severe situation and the major suffering patients with pain can be forced to live with. I would be very happy if the studies foster a more patient-centered care ethos. If some health-care provider somewhere can better help a suffering patient with chronic pain, the work has been worthwhile.

2 BACKGROUND

2.1 PAIN

The most-cited definition of pain is: “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (Merskey & Bogduk, 1994). This definition includes the subjective experience and unpleasantness associated with damage. The definition has helped generations of patients in pain to be better understood by their health-care professionals, but it may also have preserved in both parties an understanding of pain as solely negative.

Pain can also be seen as helping to maintain good health and personal growth. Acute pain is an important factor for surviving as pain induce physiological changes and protective behaviour. In the definition of acute pain, the pain disappears after the injured tissue has healed. Pain in connection to active sports or childbirth is another example of positive pain. Opponent process theory explains the phenomenon by suggesting that for “each unpleasant stimulus or emotion that triggers a negative reaction, there is also an opposite valence which has a slower onset and offset, returning the system to homeostatic balance” (Solomon, 1980). Neurobiological research into the homeostatic process in the pain sensation adds the physiological understanding of this phenomenon, confirming the theory (Craig, 2003).

2.1.1 Chronic pain

Unlike in acute pain, where nociception occurs, chronic pain has not always this obvious connection. The definition of chronic pain is, that it is lasting more than three to six months i.e. persists beyond the normal healing time (Merskey & Bogduk, 1994). Still the time-related definition of chronic pain does not take into account the fact that chronic pain may be recurrent or have more or less effect on quality of life (QoL) and disability. As pain intensity, duration and number of pain sites together with psychological and behavioural factors are prognostic for continued pain, a changed definition of chronic pain as a prognostic definition has been proposed (Pergolizzi et al., 2012).

2.1.1.1 *The biopsychosocial model*

The biopsychosocial model developed by Engel in the 1970s sought to understand disease not only as a biomedical phenomenon, but also including psychological and social factors (Engel, 1977). Today, the biopsychosocial model predominates in research on, and assessment and treatment of, chronic pain (Gatchel, Peng, Peters, Fuchs, & Turk, 2007). Despite comprehensive research, chronic pain is still something of an enigma and the biopsychosocial

model a holistic and heuristic approach to explain the complex connections between neurobiological preconditions and changes, genetics, and emotional, cognitive and sociocultural factors (Gatchel et al., 2007). Clinically, the patient's pain problem has to be seen in all dimensions and treatment should be adapted (Cheatle, 2016).

2.1.2 The complexity of chronic pain

2.1.2.1 The prevalence of chronic pain

The prevalence of chronic pain of moderate-to-severe intensity is about 20% in Europe or in American population studies (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006; L. Miller & Cano, 2009). In a Swedish cross-sectional survey 54% reported chronic pain (Gerdle, Bjork, Henriksson, & Bengtsson, 2004) and in a systematic review from the United Kingdom, chronic pain was estimated to be prevalent in 43% of the general population (Fayaz, Croft, Langford, Donaldson, & Jones, 2016). Women are more likely to suffer from chronic pain than men (Breivik et al., 2006; Gerdle et al., 2004; Tsang et al., 2008) and older age is connected with more pain (Fayaz et al., 2016; Tsang et al., 2008). Differences in prevalence studies of chronic pain are related to factors such as definition and methodology. The importance of recognising chronic pain as a global health-care problem has been stated by the International Association for the Study of Pain (IASP).

2.1.2.2 Chronic pain conditions

Nociceptive pain

Musculoskeletal pain

Musculoskeletal pain is considered the most prominent chronic pain condition (Gerdle et al., 2004). Nociceptive pain such as that based on inflammation in joints, vessels and internal organs might have local or more widespread distribution and thus have a greater or a lesser impact on the patient's life (Peolsson, Borsbo, & Gerdle, 2007). Pain can be experienced as constant aching or more intensive, well-demarcated; or triggered by motion. By their definition, common chronic-pain conditions such as fibromyalgia or non-specific chronic low-back pain lack nociceptive or neuropathic signs. Hence a third descriptor (e.g. nociplastic or algopathic) has been proposed to cover the clinical and psychophysical findings of altered nociception (Kosek et al., 2016).

Pain related to endometriosis

Endometriosis is a condition where endometrial tissue is found outside the uterine cavity.

Retrograde menstruation is one of several hypotheses about its aetiology (Vercellini, Vigano, Somigliana, & Fedele, 2014). Endometriosis is defined as a chronic, inflammatory condition, occurring in about 10% of females of fertile age (Vigano, Parazzini, Somigliana, & Vercellini, 2004). There is a wide range of conditions, from limited superficial endometrial implants to severe states, infiltrating different organs (Ferrero, Alessandri, Racca, & Leone Roberti Maggiore, 2015). The most prominent symptoms are pain and infertility (Vercellini et al., 2014).

Pain mechanisms in endometriosis are mainly nociceptive and inflammatory, possibly also with neuropathic elements (Ferrero et al., 2015). Dysmenorrhea, dyspareunia, painful defecation and dysuria are the most frequent pain problems (Vercellini et al., 2014). Endometriosis-related pelvic pain can occur intermittently, in relapses or as a constant problem.

Neuropathic pain

Neuropathic pain is defined as a direct consequence of a lesion or disease in the somatosensory system (Treede et al., 2008). About 7% of the general population are affected by chronic pain with neuropathic characteristics (Bouhassira, Lanteri-Minet, Attal, Laurent, & Touboul, 2008; Torrance et al., 2014). The aetiology of neuropathic pain lies in numerous diseases and conditions as diabetes, HIV, mechanical impingement, trauma and post-surgical complications as well as infections or vascular illness. Clinical expressions of neuropathic pain include spontaneous or evoked continuous or intermittent pain in combination with allodynia and hyperalgesia. Research on neuropathic pain and its underlying dimensions of potentially specific pathophysiology is ongoing (Bouhassira & Attal, 2016).

2.1.2.3 Comorbidity in chronic pain

Psychological symptoms are common in chronic pain conditions (Lotte Nygaard Andersen et al., 2014; Tsang et al., 2008). It has been estimated that as much as 35% of patients with chronic pain have comorbid depression (L. Miller & Cano, 2009). The connections between pain and depression are complex and a topic for discussion (Gerrits, van Oppen, van Marwijk, Penninx, & van der Horst, 2014; Linton & Bergbom, 2011). Andersen et al (2014) found in their review a more clear association between widespread pain/nonspecific pain and depression, than between specific pain and depression (Lotte Nygaard Andersen et al., 2014). Longitudinal studies have shown the synchrony of changes for anxiety and depression disorders and pain over time, but with higher pain ratings than in healthy controls by all measures (Gerrits, van Marwijk, van Oppen, van der Horst, & Penninx, 2015). In the clinic,

assessment and treatment of the co-occurring mental disorders are important (Borsbo, Peolsson, & Gerdle, 2009; Linton & Bergbom, 2011).

Attention has been given to the comorbidity of sleep disturbance and chronic pain. Insomnia has been found in 50 - 65% of patients with chronic back pain or participating in chronic pain rehabilitation programmes (Alfoldi, Wiklund, & Gerdle, 2014; Tang, Wright, & Salkovskis, 2007; Wilson, Kowal, & Ferguson, 2016). Neuro-biological findings, together with experimental, epidemiological and clinical studies show a complex and bi-directional relationship between the two conditions (Boakye et al., 2016; Sivertsen et al., 2015; Tang et al., 2007) with some indications of a stronger effect of sleep impairment on pain development than the other way round (Finan, Goodin, & Smith, 2013; Koffel et al., 2016). Until more evidence for the connections is available, and in the clinical perspective, insomnia should be included in assessment and treatment of pain sufferers (Cheatle et al., 2016; Finan et al., 2013; Sivertsen et al., 2015; Tang & Sanborn, 2014).

2.1.2.4 Disability

The chronic pain condition has physical, psychological, cognitive and social consequences, notably impairments in function, activity and participation (Lotte Nygaard Andersen et al., 2014; Borsbo et al., 2009). This is expressed in the patient's experience of limitation related to the pain itself, physical activity, fatigue, concentration difficulties and work limitations (Juuso, Skar, Sundin, & Soderberg, 2016; Löfgren, Schüldt Ekholm, Schult, & Ekholm, 2016). The fear-avoidance model has been the ruling paradigm for understanding connections between pain and disability for several decades (Lethem, Slade, Troup, & Bentley, 1983; Vlaeyen & Linton, 2012). Here the vicious circle where pain, pain catastrophising, pain-related fear, hypervigilance and avoidance induce disability and depression is explained and possible treatment with psychological interventions is clarified (Vlaeyen & Linton, 2012). An expressed need has arisen for a more comprehensive understanding of the model, including social, cultural and environmental processes (Wideman et al., 2013).

2.1.2.5 Quality of life in patients with chronic pain

Many studies show the diminished QoL related to chronic pain. Quality of life has been measured with validated, generic instruments in different pain conditions such as musculoskeletal pain (Hägg, 2003; Jansen, Linder, Ekholm, & Ekholm, 2011; Jensen, Plesner, Kvorning, Krogh, & Kimper-Karl, 2016; Peolsson et al., 2007), endometriosis (Gao et al., 2006), neuropathic pain (Manca, Eldabe, Buchser, Kumar, & Taylor, 2010; Pickering & Lepage, 2011), elderly women (Wranger, Rennemark, Berglund, & Elmståhl, 2014) and

in patients at a multidisciplinary pain clinic (Fredheim et al., 2008). To date, there is no evidence for an association between pain intensity and QoL but nonspecific pain might be associated with lower QoL (Lotte Nygaard Andersen et al., 2014). Qualitative studies and patient interviews increase knowledge of pain's influence on QoL. Pain and its consequences in diminished activity and participation, poor social and emotional functioning, as well as financial difficulties are examples of the overall effects on QoL (Lotte Nygaard Andersen et al., 2014; Breivik et al., 2006; Fredheim et al., 2008; Löfgren et al. 2016).

2.1.3 The patient's experience of chronic pain

Many qualitative studies concern the experience of chronic pain and its impact on the patient's life. Reviews, syntheses and meta-syntheses exist in diagnosis-related groups as low-back pain (Bunzli, Watkins, Smith, Schutze, & O'Sullivan, 2013; Froud et al., 2014; Snelgrove & Liossi, 2013) and fibromyalgia (Sim & Madden, 2008). Studies on musculoskeletal chronic-pain conditions show the huge impact of pain on people's lives. The 'invisibility' of pain, for example, may create problems of legitimacy and of communication with significant others and health care. As pain varies, life becomes unpredictable and daily activities limited. Pain affects the quality of sleep and induces fatigue especially in patients with fibromyalgia (Löfgren et al., 2016; Toye et al., 2013).

Knowledge of chronic visceral pain is included in systematic reviews of chronic pelvic pain (Toye, Seers, & Barker, 2014) and of endometriosis by its own (Culley et al., 2013; Denny & Khan, 2006; Young, Fisher, & Kirkman, 2014). Here the descriptions of indescribable pain, the struggle to relate to normal/pathological pain, the influence of pain on sexual activity and the culture of secrecy are findings representative of pelvic pain. The unpredictability of pain, the importance of a diagnosis and legitimacy, pain that takes control and limits physical and social life mirror patient experience of musculoskeletal pain.

Knowledge of how patients experience neuropathic pain is limited to studies mostly related to spinal-cord injury (Hearn, Cotter, Fine, & K, 2015b; Henwood, Ellis, Logan, Dubouloz, & D'Eon, 2012; Löfgren & Norrbrink, 2012), peripheral neuropathy (Brod, Pohlman, Blum, Ramasamy, & Carson, 2015), leg ulceration (Taverner, Closs, & Briggs, 2011), and unspecified neuropathic pain (Lönnstedt, Häckter Ståhl, & Hedman, 2011). Accordingly, neuropathic pain greatly affects physical and daily functioning, mental wellbeing and social relations. Patients have to deal with the pain condition as well as the problems of the underlying disease such as diabetes or spinal injury. As in other pain conditions, meetings with health-care staff are often frustrating, since patients may feel they are not believed and

not understood (Löfgren & Norrbrink, 2012; Lönnstedt et al., 2011). Of distinct importance in spinal-cord-injury-related neuropathic pain is the poor consensus regarding treatment of the pain, the insufficient pharmacological usefulness and the limited interest of health care to help with non-pharmacological, complementary interventions (Hearn, Cotter, Fine, & K, 2015; Henwood & Ellis, 2004; Löfgren & Norrbrink, 2012).

2.2 TREATMENT OF CHRONIC PAIN

2.2.1 Development of health care for pain

Specialised pain clinics were in many cases started with an anaesthesiological background, to help pain sufferers after the Second World War. Treatment was often based on nerve blocks and other pharmacological interventions (Gerbershagen, 2003). The biomedical paradigm was successful for acute pain, but in more complex chronic pain situations was insufficient (D. C. Turk, Swanson, & Tunks, 2008). Based on the biopsychosocial model, multi-disciplinary pain clinics were developed, where professionals representing different disciplines and specialties work together (Gerbershagen, 2003). At the same time, patients with chronic pain were also treated in rehabilitation clinics, where the biopsychosocial paradigm was predominant. Today patients with chronic pain are treated at different care levels and in different settings. In Sweden primary care is the first option for patients with limited problems. For specialized treatment, patients can be referred to pain clinics or rehabilitation units.

Pain clinics traditionally work unimodally or in multidisciplinary teams, partly following the biopsychosocial model. They may specialise, but often include patients with differing chronic pain conditions. Organizations can vary considerably, some being hospital-based but most working as ambulatory units. Staffs may include physicians with different specialist competences, psychologists and physiotherapists. Nurses in these teams often work in assessment, follow-up of pharmacological treatment, health counselling and as coordinators. The diversity of organizations and confusion in the definition of pain clinics, teams and interventions render comparisons between units and treatment outcome challenging.

2.2.2 Conventional treatment at pain clinics

Treatment differs depending on local conditions, team composition and the influence of individual education and experience. However, pharmacological treatment is often the basic approach and includes oral analgesics and adjuvants, peripheral nerve or regional sympathetic blocks and topically administered medicines. Treatment may be supplemented with physical

therapy and physical training, psychological interventions such as cognitive behavioural therapy (CBT) or acceptance and commitment therapy (ACT). Also employed are sensory stimulation such as transcutaneous electrical nerve stimulation (TENS), pain education and invasive interventions. Treatment can be individual or group-based.

Though pain clinics are now common, few studies have explored the heterogeneous sample of patients treated and the treatment interventions in these settings (Becker, Sjogren, Bech, Olsen, & Eriksen, 2000; Fredheim et al., 2008; Heiskanen, Roine, & Kalso, 2012; Jensen et al., 2016; Meineche-Schmidt, Jensen, & Sjøgren, 2012).

2.2.3 Multimodal rehabilitation – MMR

Rehabilitation is defined by the WHO as: “... is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides disabled people with the tools they need to attain independence and self-determination” (World Health Organization, 2016). Rehabilitation from chronic pain takes into account the complex situation of the patient, is goal-oriented and uses a holistic, multimodal approach (Swedish Council on Health Technology Assessment, [SBU] 2010). Pain reduction is desirable, but the main goal is to improve activity and participation and thus quality of life. In MMR a combination of psychological interventions with physical activity/ training, manual or physical methods is performed by a team in which the patient is an integrated participant (SBU, 2010). The team may consist of physicians, psychologists, physiotherapists, occupational therapists, social workers and nurses. The nurse’s role can also include that of coordinator. The team seeks group decisions concerning assessment and treatment planning. Patients are expected to participate actively in goal setting and to reach the set goals. The patient usually has a contact person in one of the team members (Daniel Merrick, 2012).

2.2.4 Treatment outcome

The outcome of pain-clinic interventions depends on the pain condition and the complexity of the problem and there are considerable nonspecific treatment effects such as interpersonal relationships between patient and health-care staff (Jamison, 2011). Nociceptive pain of shorter duration has several pharmacological and non-pharmacological treatment alternatives (Swedish Council on Health Technology Assessment [SBU], 2006). For chronic or generalized pain, representing more complex conditions, reviews have found evidence for the effectiveness of MMR compared to less comprehensive interventions (Scascighini, Toma, Dober-Spielmann, & Sprott, 2008; SBU, 2010). A recent Cochrane review concluded that

MMR minimized pain and disability in low-back pain, but owing to the expense, it should be reserved for patients whose pain has a significant psychosocial impact (Kamper et al., 2014).

Treatment for pain related to endometriosis can be disease-specific or for the pain as such (Kodaman, 2015). Severe pain conditions are best treated in a multidisciplinary approach (Rhodin, 2013).

Limited effects of analgesics and adjuvants and uncertain therapy response are also found in neuropathic pain (Attal & Bouhassira, 2015). Recent studies of potentially specific pathophysiology in neuropathic pain could possibly contribute to improve the treatment outcome of pharmacological interventions (Bouhassira & Attal, 2016).

Knowledge of patient's experience of treatment includes the importance of getting a diagnosis and adequate information, searching for a "quick-fix" in the early phase of treatment, and looking for adequate coping strategies as they grow to accept the pain. The significant influence of supportive meetings in health-care to increase self-confidence and let the patient be part of decision for treatment and planning are also expressed (Löfgren et al., 2016).

In conclusion, chronic pain is a complex condition with limited possibilities for a cure. Interventions taking into account all its dimensions as a biopsychosocial problem seem to be needed. This requires the presence of different professionals and specialties. The supportive personal meeting in health care should empower the patient to find ways of relief, functional coping strategies, acceptance and restored quality of life.

2.3 THE SALUTOGENETIC MODEL AND THE SENSE OF COHERENCE

The salutogenetic model developed by Aaron Antonovsky in the late 1970s considers what factors are important for individual health. Antonovsky had observed how people could stay healthy despite grave, stressful life events. His salutogenetic model of health was developed in contrast to the prevailing paradigm of pathogenesis. Antonovsky distinguished between stressor and tension, where tension can create negative stress or individual development, thus contributing to the health state. He viewed health as a continuum, from ease to dis – ease and not as a dichotomy between health and disease. Generalized resistance resources help the individual to prevent tension from being transformed into stress (Antonovsky, 1979).

Antonovsky defined sense of coherence as "a global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that one's internal and external environments are predictable and that there is a high probability that things will

work out as well as can reasonably be expected” (Antonovsky, 1979, p.123). He conceptualised sense of coherence in three components. Comprehensibility refers to how individuals view difficulties as understandable and manageability to the security of having resources available to manage stress and not be a victim of circumstances. Meaningfulness refers to an individual’s feeling of importance, worth commitment in life. The sense-of-coherence scale (SOC) became the instrument to measure the components and establish a sense-of-coherence value (Antonovsky, 1987).

Several cross-sectional and longitudinal studies have shown associations between strong SOC and better health, especially mental health in different conditions and chronic pain (Benz, Aeschlimann, & Angst, 2015; Chumbler et al., 2013; Eriksson & Lindstrom, 2006) and also between strong SOC and higher QoL and life satisfaction (Anke, Damsgard, & Roe, 2013; Eriksson & Lindstrom, 2007). Low SOC reportedly predicts postoperative pain (Badura-Brzoza, 2008; Barthelsson, Nordstrom, & Norberg, 2011). The associations between SOC and chronic pain are not conclusive, as studies show that both low SOC (Callahan & Pincus, 1995; Cederlund, Ramel, Rosberg, & Dahlin, 2010; Havermark & Langius-Eklof, 2006; Schrier et al., 2012; Wiesmann, Dezutter, & Hannich, 2014) and high SOC (Lillefjell, Jakobsen, & Ernsten, 2015) are associated with higher pain intensity. One study found no association (Malmgren-Olsson & Branholm, 2002). Few studies have explored the sense-of-coherence concept in qualitative studies of chronic disease, pain and disability (Albrecht & Devlieger, 1999; Andersen, Kohberg, Herborg, Sogaard, & Roessler, 2014; Andreassen & Wyller, 2005; Apers et al., 2016; Dahlviken, Fridlund, & Mathisen, 2015; Griffiths, Ryan, & Foster, 2011).

3 ETHICAL CONSIDERATIONS

To study patients raises ethical questions, and patients with chronic pain may be particularly vulnerable, as their condition affects many aspects of life and their experience of health-care professionals may be negatively coloured. Patients' confidence in health care often needs to be rebuilt. They may wonder whether collaboration will influence their encounters with health care and their treatment, or how their data is handled. Further, questionnaire-filling takes time, energy and can stir emotions. For patients to feel comfortable, the researcher needs to take responsibility for interviewing them not only as a researcher but also as a professional health-carer. Our studies were approved by the Regional Ethical Review Board, Stockholm (Reg.nr: 2010/1903-31/5) with supplementary applications (Reg.nr: 2012/75-32 and Reg.nr: 2013/1245-32). The participants were adults who received oral and written information about the study. They were informed that they could withdraw at any moment. Prior written consent was obtained. They could contact the researcher during ordinary working hours (study II) or at any time (studies I and III) if needed. For written comments in the follow-up questionnaires, such as negative contact with the clinic or insufficient treatment outcome, the researcher telephoned to ensure that any necessary health care support was available. Being interviewed in a research project can be experienced as important for others and fruitful for oneself (Kvale & Brinkmann, 2009). This became obvious in the present interviews, when particularly the informants in the endometriosis study expressed both the importance of contributing to increase knowledge of the disease and the utility of the interview for themselves.

4 AIMS

The overall aim of the work presented in this thesis was to explore aspects of living with chronic pain among patients attending a pain clinic.

4.1 SPECIFIC AIMS

Study I

Paper I sought to explore how patients experience activity, participation and quality of life one year after the start of a multimodal rehabilitation programme at a pain clinic, and what impact this has had on their ability to manage daily life.

Study II

Paper II aimed to describe characteristics of patients with complex chronic pain problems treated with a multimodal rehabilitation programme at a conventional pain clinic. It also sought to evaluate patient-reported outcome measures after one year. A secondary aim was to identify predicting factors for the improvement of health-related quality of life at follow-up.

Paper III aimed to describe patients at a pain clinic, to follow them from their first visit to one year later and to identify associations between baseline characteristics and improved health-related quality of life in the follow-up.

Study III

Paper IV aimed to explore women's experience of painful endometriosis and its treatment.

5 METHODS

Both qualitative and quantitative approaches were used. To ensure patients' perspectives, patient interviews and patient-reported outcome measures (PROM) were included. An overview of the studies is shown in Table 1.

Table 1. Overview of the studies

Study	Paper	Design	Study population	Data collection	Data analysis
Study I	Paper I	Qualitative emergent	14 informants (13 females) from the patients in MMR one year earlier, purposively sampled.	14 semi-structured interviews and information from patients' records.	Inductive, content analysis
Study II	Paper II	Prospective, longitudinal, observational	42 patients (38 females) treated with MMR.	PROM at first visit and one year later, plus information from patient records.	Descriptive statistics, Wilcoxon signed-rank test, Fisher's exact test, Mann-Whitney U-test, Logistic regression
	Paper III		271 patients treated with CPT and 47 patients, assessed and re-referred.		
Study III	Paper IV	Qualitative emergent	13 informants with endometriosis treated with CPT, purposively and theoretically sampled.	16 semi-structured interviews and information from patients' records.	According to grounded theory

5.1 SUBJECTS AND CONTEXT

The hospital-based out-patient pain clinic where all the present studies were performed is situated in Stockholm, Sweden. The team consisted of physicians specialising in algology, anaesthesia, general medicine and rehabilitation medicine, nurses specialising in intensive care and educated in pain treatment, a physiotherapist with education in ACT, a psychologist and a secretary. There was collaboration with two external physio units from which physical therapists and an occupational therapist participated in the multimodal rehabilitation programme (MMR).

Adult patients were referred to the clinic from primary care, specialist units, and occupational health-care centres. A prerequisite for assessment and treatment at the pain clinic was a complete medical examination and previous treatment of the underlying disease. The assessment was done in several steps: referrals were assessed by an interdisciplinary team and a preliminary assessment of patients needing intervention was done. Patients accepted for a visit were invited to a first appointment. This included a biopsychosocial pain analysis and an individualised treatment plan. The plan was then sent to the referring physician for information. Patients identified as in need of more comprehensive treatment were invited to an assessment visit with all the MMR team members. Patients who after initial conventional pain treatment needed more comprehensive interventions could be included in the MMR later.

Patients referred for assessment only (AO), identified at the first visit as being in need of minor or suitable interventions at other health-care facilities, were referred back to their physicians. The treatment alternatives at the pain clinic were either conventional pain treatment (CPT) or MMR. CPT, the principle treatment alternative, was mainly pharmacological but could include extended treatment such as TENS, interventions by the psychologist or participation in a pain self-management course. Indications for MMR were complex pain problems with significant impact on daily function, activity level and participation and thus quality of life. Further, the patient had to show openness to behavioural change and sufficient knowledge of Swedish to manage the verbal parts of the MMR. MMR was individually adapted and consisted of participation in the pain self-management course, physical training, CBT or ACT and adjusted pharmacological therapy. A personal contact person supported the patient to identify and follow-up her or his rehabilitation goal. The patient participated in activities during 4-6 hours each week for three months. Team meetings were held regularly.

5.2 DATA COLLECTION

5.2.1 Inclusion

The inclusion process is shown in Figure 1. Inclusion criteria for all studies were patients at their first visit to the outpatients' pain clinic, pain lasting >3 months, age ≥ 18 years and assessment or assessment- plus-treatment at the pain clinic. Exclusion criteria were severe illness with expected survival <6 months and cognitive impairment assessed with the Short Portable Mental Status Questionnaire. Inclusion criteria for papers I and II were also participation in the MMR, and in paper III CPT, or assessment at the clinic. Three months

after inclusion, the author reviewed the patient`s records and identified him or her as belonging to the different treatment groups at the three-month time point. To ensure the correct treatment category, the record was checked one year after inclusion. In paper IV informants with painful endometriosis from the CPT-group were included. Following theoretical sampling (Corbin & Strauss, 2008), two women not included in the questionnaire study, but with ongoing CPT, were also interviewed.

Data were collected between 2011 and 2016. For study II patients were included from April 2011 until March 2013 and the follow-up was finished in March 2014 (Papers II and III). The interviews were performed between May 2012 and January 2013 (Paper I) and between February 2015 and March 2016 (Paper IV).

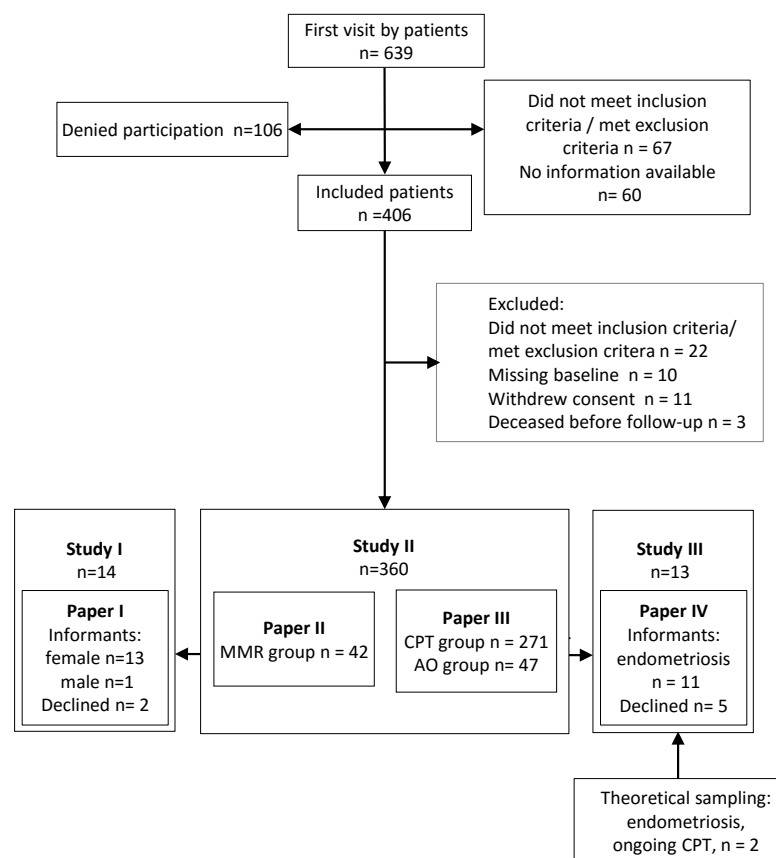


Figure 1: Overview of the studies and papers and the inclusion process of patients attending and assessed at the pain clinic and participating in different treatment alternatives.

5.2.2 Interviews

The qualitative studies aimed to explore experience and importance of pain treatment on activity, participation and quality of life. The interviews were therefore performed one year after (Study I) to several years after (Study III) treatment at the pain clinic. They were semi-

structured (Kvale & Brinkmann, 2009; Price, 2002) and followed emergent design, the question guides being expanded during the analysis in both qualitative studies (Dahlgren, Emmelin, Winkvist, & Lindhgren, 2007).

The interviews were performed at places to suit the patients. Twenty-two interviews were held in a private room at the hospital, six in the informants' homes, one at the informant's workplace and one in a public library. Most of the interviews were done by the author, and the principal supervisor contributed with seven interviews. The interviewers were not involved in the patients' care. The interviews were digitally recorded and transcribed verbatim. After each interview, the interviewer noted down her observations, feelings and thoughts about the informant, the circumstances and the interview. These notes were shared with the co-authors.

5.2.3 Patient-reported outcome measures

Data were collected with seven patient-completed, validated instruments in Swedish translations (Table 2). Further questions about education, country of origin, livelihood, pain localization, duration and intensity corresponded to those in the Swedish Quality Registry of Pain Rehabilitation questionnaire (Swedish Quality Registry for Pain Rehabilitation, [SQRP] 2010). The questionnaire was handed out to the patients at their first visit to the pain clinic and mailed to the patients for the one-year follow-up. Two reminders were sent if answers were not received after two weeks. Information about age, gender, pain condition and treatment were collected during the review of patient records described above.

5.2.3.1 Validated instruments

Health-related quality of life

The EuroQol-5D-3L questionnaire (EQ-5D) is a generic instrument for describing and evaluating present health-related quality of life (HRQoL) in the dimensions mobility, self-care, usual activities, pain/discomfort and anxiety/depression (Rabin & de Charro, 2001; The EuroQol Group, 1990). The EQ-5D index, based on the English value set, was our primary outcome (Dolan, 1997). A minimal clinical change (MCIC) was estimated to be 0.1 (Walters & Brazier, 2005).

The second part of the EQ-5D rates present health state (EQ VAS) on a 0-100 'thermometer' scale, with endpoints 'worst imaginable health state' and 'best imaginable health state', respectively (Rabin & de Charro, 2001).

Table 2. The instruments used for patient-reported outcome measures

Domain	Instrument	Description	Total score Min-max	Cut-off for severity levels	Minimal clinical important changes
Health-related quality of life generic instrument	EuroQual	Dimensions: mobility, self-care, usual activities, pain/discomfort, anxiety/depression	-0.594 - 1		0.1
	5 Dimension index (EQ-5D Index)	Levels: no problems = 1, some problems =2, extreme problems =3. Health-status-weighted-index calculation based on English values.			
	EuroQual Visual Analogue Scale (EQ VAS)	20 cm vertical scale with endpoints “worst imaginable health state” (0) and “best imaginable health state” (100)	0 - 100		
Current pain intensity	Visual Analogue Scale (VAS)	100 mm horizontal visual analogue scale with the endpoints “no pain” to “worst imaginable pain”. Marks converted to a number 0-100.	0 - 100	Pain interference with function: ≤ 34 = mild 35 - 64 moderate ≥ 65 severe	18 - 19
Mental health screening questionnaire	Hospital Anxiety and Depression Scale (HADS-A, HADS-D)	Anxiety subscale, different statements in relation to anxiety, four levels of severity.	0 - 21	No anxiety/ depression 0 - 7	
		Depression subscale, different statements in relation to depression, four levels of severity.	0 - 21	doubtful cases 8 - 10 definite cases 11 - 21	
Insomnia screening and treatment outcome questionnaire	Insomnia Severity Index (ISI)	Dimensions: sleep onset, sleep maintenance, early morning awaking problems, sleep dissatisfaction, interference of sleep with daily activity, sleeping problems interfering with quality of life noticeable by others, distress due to sleep problems during the last two weeks Likert scale from no problems, = 0 to severe problems = 4	0 - 28	No insomnia ≤ 7 sub-threshold 8 - 14 moderate 15 - 21 severe insomnia \geq 22	6 - 8.4
Pain-related disability	Pain Disability Index (PDI)	Domains: family/home responsibility, recreation, social activities, occupation, sexual behaviour, self-care, life-support activity Likert scales from no disability = 0 to worst disability =10	0 - 70		8.5 - 9.5
Kinesiophobia	Tampa Scale of Kinesiophobia (TSK)	17 items concerning fear of movement and (re) injury Likert scale from strongly disagree =1 to strongly agree = 4	17 - 68	Low kinesiophobia 17 - 33 mild 34 - 41 high 42 - 68	
Sense of Coherence	Sense of Coherence (SOC)	Based on Antonovsky’s Sense of Coherence concept. 13 items to assess individual view of life as comprehensible, manageable and meaningful. Likert scale from 1-7.	7 - 91	Weak SOC ≤ 57 moderate 58 - 74 strong SOC ≥ 75	

Pain intensity

A 100 mm horizontal visual analogue scale (VAS) with the endpoints ‘no pain’ and ‘worst imaginable pain’ to assess current pain intensity (Breivik et al., 2008; Woodforde & Merskey, 1972) was used. Pain VAS levels interfering with function have been found in patients with chronic pain (Boonstra, Schiphorst Preuper, Balk, & Stewart, 2014) and MCIC in low-back pain (Hagg, Fritzell, & Nordwall, 2003)

Mental health

The Hospital Anxiety and Depression Scale is used to assess mental health (HADS) (Zigmond & Snaith, 1983). The questionnaire was developed to screen emotional disturbances in a clinical population with physical illness and has shown validity and reliability in different contexts (Bjelland, Dahl, Haug, & Neckelmann, 2002; Zigmond & Snaith, 1983). HADS consists of 7 items related to anxiety and 7 items for depression. Each item represents a statement which can be scored at one of four severity levels. The scores are transferred and summed to a total score for each subscale. Cut-off values for caseness of anxiety disorders and depression are described (Bjelland et al., 2002).

Insomnia

The Insomnia Severity Index (ISI) questionnaire is used to detect insomnia in community or clinical settings and to evaluate treatment (Bastien, Vallieres, & Morin, 2001; Morin, Belleville, Belanger, & Ivers, 2011). The ISI assesses the nature, severity and impact of insomnia during the previous two weeks in seven domains including sleep onset and maintenance, early morning awakening problems, and interference of sleep with daily activity. It is scored on a 5-point Likert scale ranging from 0 = no problems to 4 = very severe problems and summed to a total score. Cut-off levels for severity (Morin et al., 2011) as well as MCIC have been described (Wilson et al., 2016; Yang, Morin, Schaefer, & Wallenstein, 2009)

Pain disability

To assess pain-related disability, the 7-item Pain Disability Index (PDI) questionnaire is suitable (Mewes et al., 2009; Tait, Chibnall, & Krause, 1990). The patient assesses how pain usually affects function in different everyday activities on a 10-point Likert scale from no disability (0) to worst disability (10). The scores are summed to a total (range 0-70). MCIC in chronic back-pain has been described (Soer, Reneman, Vroomen, Stegeman, & Coppes, 2012).

Kinesiophobia

Fear of movement and (re)injury is measured with the Tampa Scale of Kinesiophobia (TSK) (Bunketorp, Carlsson, Kowalski, & Stener-Victorin, 2005; P. K. Miller, S. Todd, D., 1991). The TSK includes 17 items, which are assessed on a 4-point Likert-scale ranging from 'strongly disagree' to 'strongly agree'. Ratings are summed (range 17-68) a higher score indicating greater kinesiophobia. Different cut-off levels for kinesiophobia are described, with three severity levels found in chronic back pain (Luning Bergsten, Lundberg, Lindberg, & Elfving, 2012).

Sense of coherence

The Sense of Coherence scale (SOC) is based on Antonovsky's salutogenetic model (Antonovsky, 1979, 1987). The original scale with 29 items has been shortened to a 13-item version (Eriksson & Lindstrom, 2005; Feldt et al., 2007) which was used in our study. The items are formulated as questions where the person has to rate his or her feelings on a Likert scale (1-7 points). The scores can be added either to a total score or to three subscales representing the different components of the concept. Cut-off levels in chronic pain have been described (Lillefjell et al., 2015).

In addition: pain localisation

The presence of pain was assessed using questions from the SQRP (2010). Patients are asked to mark their pain localisations in descriptions of 18 areas of both the right and the left half of the body (total 36 areas) which are summed to number of pain sites (NPS). Further, patients indicate one of 11 possibilities as their worst pain area.

5.3 DATA ANALYSIS

Short descriptions of the analysis are given below, with more details in the papers.

5.2.4 Content Analysis (Paper I)

Content analysis is defined by Krippendorff as "a research technique for making replicable and valid inferences from texts (or other meaningful matter) to the contexts of their use" (Krippendorff, 2004, p.18). The data can be verbal text, symbols or whatever is communicated and found to be a source of knowledge about a phenomenon. Content analysis characteristics are its empirically grounded, exploratory process and its own methodology (Krippendorff, 2004). Content analysis was initially developed to describe quantitative data in e.g. journalistic texts. Later its use was extended to involve qualitative data from different

sources in many disciplines such as psychology, sociology and nursing (Elo & Kyngäs, 2008).

Given the complexity and limited knowledge of patients' experience of pain rehabilitation we used inductive, qualitative content analysis ad modum Elo and Kyngäs (Elo & Kyngäs, 2008) in study I. The analysis included listening to and reading each interview, dividing it into meaning units and coding these. Then the codes were sorted into subcategories and categories. Further the relations between the categories were explored and themes developed. The freeware Open Code 3.6 (ICT Services and System Development and Division of Epidemiology and Global Health, 2013) was used for coding and abstraction. After 12 interviews, saturation was reached within the main themes, and the last two interviews confirmed these results. By returning to the interviews and comparing with the results, the findings were confirmed by the original data. During the whole process the results were discussed regularly by the authors.

5.2.5 Grounded theory (Paper III)

The grounded theory was developed by Glaser and Strauss in the 1960s to systematically create theory from data in medical sociology (Glaser & Strauss, 1967). Grounded theory is used to explore human experience and describe it at an abstract level. It is a conceptual method, where tools are developed to understand and describe problems and situations by their underlying actions, interactions and consequences in a studied area (Corbin & Strauss, 2008). Different trends in grounded theory arose during the following decades, illuminating the complexity of qualitative research. The key belief in all grounded theory methods is to set aside theoretical ideas and develop the concepts through constant and theoretical comparison (Corbin & Strauss, 2008).

Grounded theory (Corbin & Strauss, 2008) was employed in the present study III. The transcripts were coded and the codes merged into sub-categories and categories using the Open Code 4.03 (ICT Services and System Development and Division of Epidemiology and Global Health, 2013) and a preliminary theory was formed from the categories. The categories with their properties and dimensions were defined by comparison with the original data. During data collection and analysis, memos were written and constant comparison used to compare codes, sub-categories and categories with one another and with the emerging theory. The early categories and subcategories were merged into one core category formed by three categories in the final theory. Conceptual saturation was reached after 14 interviews and the last two interviews confirmed earlier findings. In the next step the core category was

further defined and connections to, and interactions with, the other categories explored. The theory was continuously refined by comparison with the data and discussions between the authors and health-care peers experienced in treating women with painful endometriosis.

5.2.6 Statistics

In all the studies descriptive statistics was used to describe the participants' / informants' demographics. The questionnaire studies were analysed with statistical methods: descriptive statistics for patients' PROM at baseline and follow up, test of significance for changes over time and comparing groups. Associations between baseline PROM and improvement in EQ-5D Index in the follow up were explored by logistic regression analysis.

The SPSS version 22 software was used for all data analysis. As all the questionnaires concern patient-reported measures, mainly non-parametric statistics were used. P-values of <0.05 (two-sided) were considered to be significant.

Changes over time and comparison of groups

To analyse the change between baseline and follow-up, the Wilcoxon signed-rank test was used. Differences between groups (Paper III) were tested using Fisher's exact test for categorical data and the Mann-Whitney U-test for continuous data. To investigate possible bias due to missing data, we compared demographics and baseline values of the PROM between the responders with valid values at baseline and follow-up and the dropouts with missing PROM values at baseline or follow-up (Papers II and III).

Analysis of associations

To study the association between the independent variables (age, gender, country of origin, education and PROM) and EQ-5D Index increase, logistic regression analysis was performed in the MMR and CPT-groups. To dichotomize the EQ-5D Index, the minimal clinically important change (MCIC) of 0.1 described earlier (Walters & Brazier, 2005) was used to differentiate between increased and unchanged/decreased.

The independent variables HADS, ISI, and TSK were dichotomized in accordance with the cut-off points previously described. EQ VAS, PDI and number of pain sites were dichotomized with reference to clinically important states represented in the data. SOC was categorized according to cut-off points described earlier (Paper II) and in the first and third quartiles (Paper III). Education and country of origin were categorized as primary/secondary school versus university and Sweden versus abroad. Age was categorized as ≤ 40 years

versus ≥ 41 (Paper II) and ≤ 41 , 41 - 65 and ≥ 66 years (Paper III). In paper I the reference was the group with a lower proportion of individuals with increased EQ-5D Index, while in paper III the clinical state representing best health was used as reference in all outcomes.

First the univariable association between improvement in EQ-5D Index and each of the independent variables was studied, followed by a multivariable analysis of the outcome and all independent variables (Paper II). In paper III, the statistically significant variables (ISI, PDI and SOC) from the crude analysis were entered into a multivariable model together with age and gender. We report odds ratios (OR) and corresponding 95% confidence intervals. To measure the model fit, a Hosmer and Lemeshow test was performed.

6 RESULTS

The studies describe different aspects of living in patients with chronic pain attending a pain clinic, possible changes shown in the follow-up of different treatment alternatives and patients' reported experience of meetings in this context. Summaries of the main findings, together with some results not included in the papers are shown below. The three studies resulted in four papers, which give more details of the findings.

6.1 “CHANGE IS POSSIBLE”: PATIENTS' EXPERIENCE OF A MULTIMODAL CHRONIC PAIN REHABILITATION PROGRAMME (PAPER I)

The aim of the study was to describe patients' experience of an MMR about one year earlier. The analysis of 14 individual interviews (13 female, one male, age mean 46, min–max 23–77) resulted in one core theme, formed of five themes, eight categories and several subcategories (Figure 2).

In the core theme “Change is possible” informants' experience before, during and after the MMR were found. Informants described how life could change from “Ruled by pain”, via “The penny's dropped” to “Live a life, not only survive”. Informants also remembered life before the pain as “A good life” and thought about their future as “Don't know but hope”.

The wide-ranging experience started with the memories of self as “Happy and strong”, able to help others, before pain changed their lives. With pain, life was a constant struggle against symptoms such as ache, stress, anxiety and fatigue. These affected the informant's self with consequences also for significant others. Daily life was limited and mental health affected. The experience of health care was mainly negative, when the informants were met by unsympathetic staff and had to wait for referrals to pain specialists.

During the MMR the informants met a turning point, when they could understand relations between their pain and living. They got explanations and legitimacy for the pain and they became aware of their own strength and responsibility for living. In meetings with understanding health- care staff, significant others and fellow patients, the informants got knowledge, skills and support to manage life. Treatments such as pharmacological or psychological therapy, participation in the pain management course or own use of TENS could be experienced as helpful. Negative side-effects of medicine gave the informants an ambivalent attitude to pharmaceuticals.

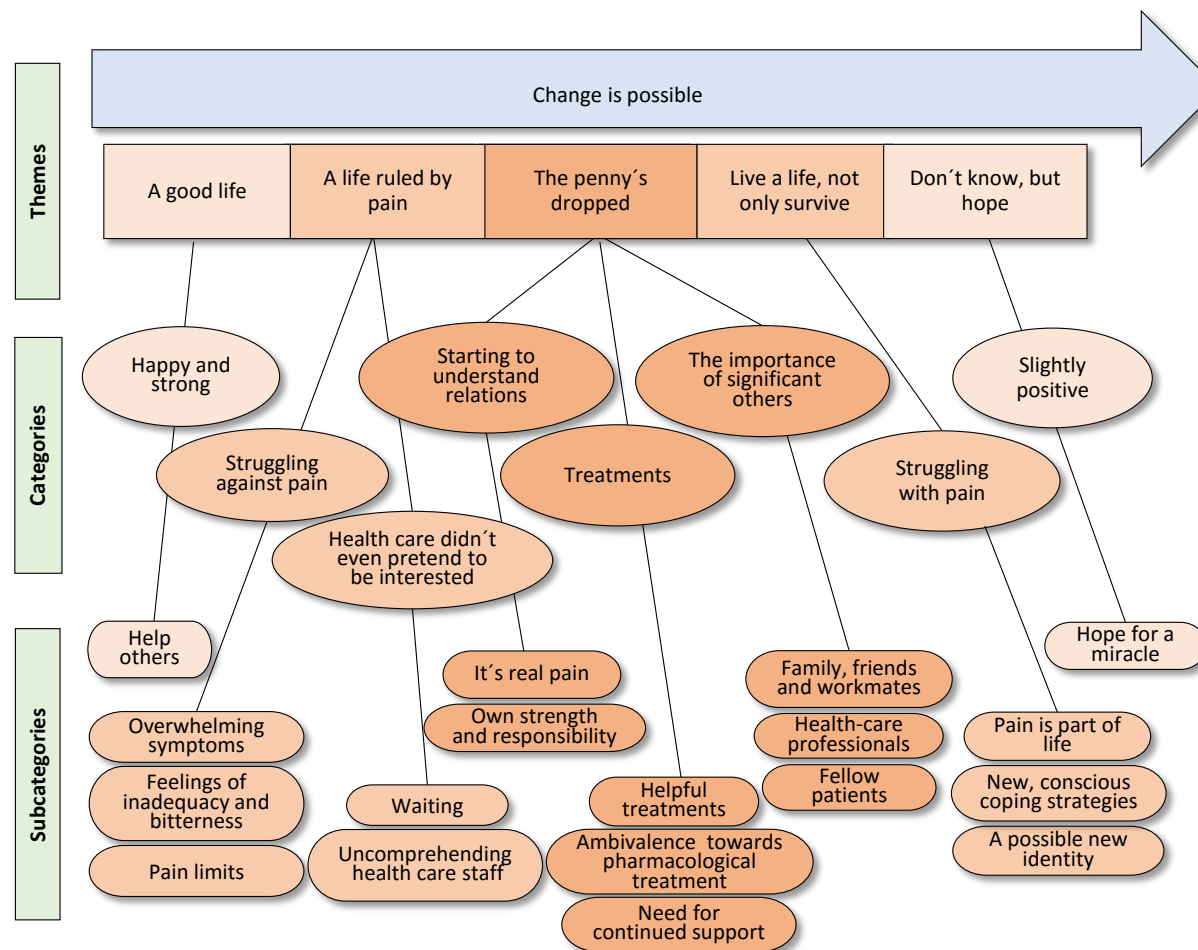


Figure 2. Patients' experience of a MMR for chronic pain. The changing process found in the core theme is visualized by the arrow. The five phases of the change are described in themes and their contents in categories and subcategories.

At the time of the interviews, the informants described being as “Live a life, not only survive”. They could see “Pain is a part of life”, had found new, conscious coping strategies and developed a new identity. Now it was a “Struggle with pain”, allowing them a functioning daily life though they could still be in pain. Thoughts about the future were slightly positive, also including a hope for a miracle to get free from pain.

Some informants did not experience this changing, felt in much pain and were still in a state of struggle against pain. However their descriptions indicated greater activity than before MMR.

6.2 PATIENTS WITH CHRONIC PAIN: ONE-YEAR FOLLOW-UP OF PATIENTS AT A PAIN CLINIC (PAPERS II AND III)

In this longitudinal, observational questionnaire study, 360 patients were followed from their first visit to the pain clinic to one year later. The data collection included PROM and information from patient records. Data analysis was performed in three groups:

- patients who participated in MMR, n= 42, female 90%, age mean 44, min-max 20-76 (Paper II)
- patients assessed and treated with CPT (CPT-group), n= 271, female 64%, age mean 50, min-max 19-86, (Paper III)
- patients assessed at the pain clinic and referred (AO-group), n= 42, female 64%, age mean 53, min-max 21- 84, (Paper III).

6.2.1 Baseline assessment

The patients showed complex and heterogeneous pain categories as found in the CPT-group, where mixed pain conditions were represented in 24% (n= 73). Solely neuropathic pain was found in 29% (n= 88), nociceptive pain in 16% (n= 50), visceral pain in 13% (n= 40) and other aetiology in 18% (n= 56). In 11 patients no information about the pain condition was available.

Characteristics and PROM from patients remitted to a pain clinic and accepted for an assessment visit are shown in Tables 3 and 4. The complex condition of chronic pain affected mental health and sleep, influencing HRQoL so that disability became obvious. Significant differences between the MMR-group and the CPT-group were found in gender (more females in MMR) and age (younger patients in MMR) as well as in several PROM, pain duration and

number of pain sites. The AO-group did not differ from the CPT-group except for ISI, where the CPT-group showed more severe insomnia.

Table 3. Patients' demographics, pain duration and number of pain sites at baseline; n (%)

		MMR-group	CPT-group	AO-group	p-value* MMR/CPT	P-value** CPT/AO
Gender	Female	38 (90.5)	173 (64)	30 (64)	<0.001	1.000
	Male	4 (9.5)	98 (36)	17 (36)		
Age	Median (q1- q3)	46 (34–52)	48 (37–62)	53 (44–63)	0.032	0.156
Country of origin	Sweden	32 (76)	221 (83)	42 (91)	0.298	0.467
	Europe	4 (10)	20 (8)	2 (4)		
	Outside Europe	6 (14)	27 (10)	2 (4)		
	Missing	0	3	1		
Education	Elementary school	7 (17)	39 (15)	9 (21)	0.428	0.405
	Secondary school/ vocational training	22 (52)	117 (44)	22 (50)		
	University	9 (21)	102 (38)	13 (30)		
	Other	4 (10)	8 (3)	0		
	Missing	0	5	3		
Pain duration	≤ 6 months	2 (5)	25 (10)	5 (18)	0.033	0.342
	7-24 months	5 (12)	59 (23)	7 (25)		
	≥25 months	35 (83)	168 (67)	16 (57)		
	Missing	0	19	19		
Number of pain sites	Median (q1 – q3)	15 (10–21)	7 (4 – 12)	6 (4 – 12)	<0.001	0.410

*p-value MMR-group compared with CPT-group, ** p-value CPT-group compared with AO-group. Nominal data tested with Fisher's exact test, and continuous variables tested with Mann-Whitney U-test.

Table 4. Patient-reported outcome measures at baseline and comparison between groups.

Instrument	MMR- group (n=42)		CPT- group (n=271)		AO-group (n=47)		p-value *	p-value**
	n	Median (q1 – q3)	n	Median (q1 – q3)	n	Median (q1 – q3)	MMR/CPT	CPT/AO
EQ-5D index	39	-0.005 (-0.077 – 0.159)	249	0.157 (0.030 – 0.673)	42	0.159 (0.030 – 0.666)	<0.001	0.585
EQ VAS	39	30 (15 – 45)	225	40 (30 – 61)	40	50 (23 – 74)	<0.001	0.489
VAS current pain	39	62 (49 – 77)	260	58 (31 – 72)	46	38 (17 – 75)	0.080	0.082
HADS anxiety	41	10 (7 -13)	257	8 (5 – 11)	46	6 (3 – 11)	0.013	0.152
HADS depression	39	10 (7 -13)	261	7 (4 – 10,5)	43	6 (2 – 10)	0.002	0.207
ISI	40	19 (15 – 25)	255	17 (12 – 21)	47	13 (9 – 19)	0.026	0.020
PDI	37	41 (30 – 52)	239	36 (26 – 47)	41	35 (23 – 42)	0.059	0.319
TSK	35	41 (33 – 49)	241	39 (33 – 46)	42	37 (31 – 43)	0.321	0.209
SOC	37	49 (42 – 59)	237	59 (49 – 68.5)	40	60 (52 – 72)	0.002	0.709

*p-value MMR-group compared with CPT-group, ** p-value CPT-group compared with AO-group. Presented with median (q1-q3) and tested with Mann-Whitney U-test.

Baseline values of the patient-reported outcome measures of the CPT-subgroup of women with endometriosis are found in Table 5.

Table 5. Baseline PROM of women with endometriosis treated with CPT

Instrument	n	Median	q1-q3
EQ-5D Index	24	0.157	0.088 – 0.689
EQ VAS	26	48	34 – 61
VAS current pain	27	37	22 – 64
HADS anxiety	26	8	5 – 12
HADS depression	26	7	3 – 10
ISI	28	17	14 – 22
PDI	24	38	25 – 44
TSK	24	36	29 – 41
SOC	27	59	44 – 67

q1: first quartile; q3: third quartile

6.2.2 Changes over time

The one-year follow-up showed statistically significant changes in EQ-5D Index, EQ VAS, ISI, PDI and TSK in the MMR-group (Table 6a). The CPT-group improved in the same PROM and in VAS (Table 6b). The AO-group showed no significant changes in any measures.

Table 6a. Changes in PROM from baseline to follow-up

MMR-group						
Baseline			Follow-up			
Instrument	n	md	q1 – q3	md	q1 – q3	p-value
EQ-5D-index	29	0.03	-0.077 – 0.354	0.587	0.004 – 0.690	0.003
EQ VAS	24	36	21 – 49	63	30 – 70	0.011
VAS current pain	27	58	48 – 72	50	32 – 65	0.075
HADS anxiety	29	10	8 – 12	10	6 – 13	0.534
HADS depression	27	10	8 – 13	8	5 – 12	0.062
ISI	26	19	15 – 25	15	11 – 19	0.008
PDI	25	41	27 – 50	33	21 – 48	0.032
TSK	25	41	32 – 48	35	29 – 42	0.020
SOC	26	49	43 – 61	54	42 – 62	0.484

Only patients with values at both baseline and the one-year follow-up are presented.

Table 6b. Changes in PROM from baseline to follow-up

Instrument	CPT-group					
	Baseline			Follow-up		
	n	md	q1 – q3	md	q1 – q3	p-value
EQ-5D-index	175	0.157	0.088 – 0.656	0.620	0.088 – 0.725	<0.001
EQ VAS	140	40	30 – 60	49	30 – 70	0.024
VAS current pain	185	57	30 – 73	48	21 – 69	0.002
HADS anxiety	175	7	4 – 11	7	4 – 11	0.401
HADS depression	184	7	4 – 10	7	3 – 11	0.814
ISI	176	16	12 – 21	15	9 – 20	0.001
PDI	158	36	25 – 46	32	18 – 43	<0.001
TSK	156	38	33 – 46	35	30 – 43	<0.001
SOC	163	59	50 – 69	60	50 – 70	0.951

Only patients with values at both baseline and the one-year follow-up are presented.

Proportions of patients in whom the PROM estimates were unchanged, improved or deteriorated from baseline to one-year follow-up are shown in Table 7.

Table 7. Patients unchanged, improved or worsened from baseline to follow-up n (%).

Instrument	MMR-group			CPT-group		
	Unchanged	Improved	Worsening	Unchanged	Improved	Worsening
EQ-Index changes >0.1	11 (38)	15 (52)	3 (10)	79 (45)	72 (41)	24 (14)
EQ VAS changes >10	9 (37)	11 (46)	4 (17)	74 (53)	42 (30)	24 (17)
VAS current pain, changes >10	10 (37)	12 (44)	5 (19)	72 (39)	72 (39)	41 (22)
HADS anxiety *	7 (29)	10 (42)	7 (29)	49 (48)	31 (30)	23 (22)
HADS depression*	12 (57)	9 (43)	0 (0)	46 (44)	25 (24)	33 (32)
ISI*	8 (38)	12 (57)	1 (5)	51 (41)	49 (39)	25 (20)
PDI, changes >9	9 (36)	12 (48)	4 (16)	85 (54)	53 (33)	20 (13)
TSK*	6 (35)	9 (53)	2 (12)	57 (47)	47 (39)	17 (14)

*Changes from one severity group to another. Only data from patients indicating disturbances at baseline or follow-up are included in the analysis.

6.2.3 Associations

The associations between baseline characteristics (demographics and PROM) and improved EQ-5D Index >0.1 were explored. Low EQ-5D Index, severe insomnia, high disability and moderate SOC were associated with an increased EQ-5D Index in the follow-up in the univariable model of the CPT-group. When the significant variables of ISI, PDI and SOC were adjusted for age and gender, only ISI remained significant (Table 8).

Table 8. Associations between improvement in EQ-5D Index and baseline variables in the CPT-group.

		Univariable model				Multivariable model		
		n total/ (% with improvement in EQ-5D Index*)	OR	95 % CI	p-value	OR	95 % CI	p-value
Age	41- 65 yrs. vs ≤ 40 yrs.	91 (40) / 41 (44)	0.8	0.4 – 1.8	0.639	0.6	0.3 – 1.5	0.308
	≥ 66 yrs. vs ≤ 40 yrs.	43 (42) / 41 (44)	0.9	0.39 – 2.2	0.850	1.3	0.6 – 2.6	0.675
Gender	Female vs male	110 (45) / 65(35)	1.5	0.8 – 2.8	0.235			
Country of origin	Abroad vs Sweden	30 (50) / 143 (39)	1.6	0.7 – 3.4	0.275			
Education	Primary/secondary school vs university	106 (41) / 66 (42)	0.9	0.5 – 1.7	0.810			
EQ-5D Index	≤ 0.3 (low) vs ≥ 0.31 (high)	113 (56) / 62 (15)	7.4	3.3 – 16.5	<0.001			
EQ VAS	≤ 32 (low) vs ≥ 33 (high)	51 (35) / 93 (43)	0.7	0.4 – 1.5	0.367			
VAS current pain	≥ 65 (severe) vs ≤ 64 (mild/moderate)	63 (41) / 105 (40)	1.1	0.6 – 1.99	0.871			
ISI	≥ 22 (severe) vs ≤ 21 (No problems/sub-threshold/moderate)	39 (56) / 127 (35)	2.4	1.1 – 4.9	0.021	3.5	1.3 – 9.2	0.013
PDI	≥ 41 (high) vs ≤ 40 (low)	59 (53) / 97 (36)	1.96	1.01 – 3.8	0.045	1.7	0.8 – 3.96	0.198
HADS anxiety	≥ 11 (definite cases) vs ≤ 10 (no/doubtful cases)	43 (37) / 123 (42)	0.8	0.4 – 1.7	0.561			
HADS depression	≥ 11 (definite cases) vs ≤ 10 (no/doubtful cases)	38 (37) / 133 (41)	0.8	0.4 – 1.7	0.617			
TSK	≥ 42 (high) vs ≤ 41 (low/mild)	58 (43) / 99 (37)	1.3	0.7 – 2.5	0.479			
NPS	General ≥ 5 pain sites vs local ≤ 4 pain sites	115 (40) / 60 (43.3)	0.9	0.5 - 1.6	0.671			
SOC	≤ 49 (weak) vs ≥ 70 (high)	32 (19) / 40 (14)	2.1	0.7 – 5.8	0.168	0.8	0.2 – 3.3	0.796
	50 – 69 (moderate) vs ≥ 70 (high)	84 (67 / 40 (14)	3.6	1.5 – 8.5	0.003	2.2	0.8 – 5.8	0.115

Analysis performed with logistic regression analyses

* Improvement in EQ-5D Index ≥ 0.1 difference between baseline and 1-year follow-up.

6.3 “TEARS INCLUDED” – WOMEN'S EXPERIENCE OF PAINFUL ENDOMETRIOSIS AND ITS TREATMENT (PAPER IV)

The study aimed to explore women's experience of painful endometriosis and its treatment. Accordingly, an interview study was performed. Twenty-nine women in the CPT-group had a diagnosis of endometriosis. Their median age was 32 (min - max 20 - 52); for baseline PROM see Table 5. Eleven of these women were included. After study II was completed two more informants were selected from the patients conventionally treated for painful endometriosis.

The qualitative analysis of 16 interviews resulted in a theory illustrating women's experience of living with painful endometriosis and its treatment (Figure 3). The theory includes one core category and three categories. Examples of properties and dimensions of the categories are found in Table 9.

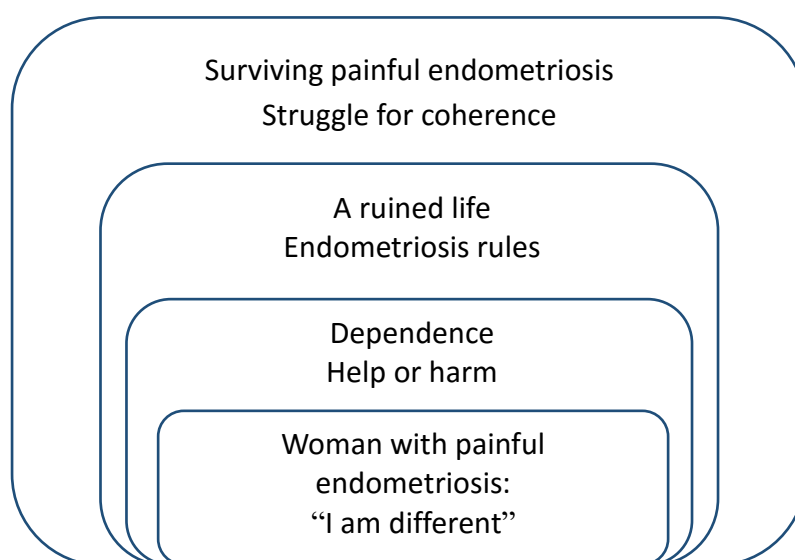


Figure 3: The theory of women's experience of endometriosis and its treatment. The struggle for coherence in the core category “Surviving painful endometriosis” is formed by the categories “Woman with painful endometriosis”, “Dependence” and “A ruined life”.

In the category “Woman with painful endometriosis”, the women described a feeling of being different from other women. Their body with pain, bleeding and fatigue was a source of questions and the feeling that something was wrong and unpredictable. Obvious signs such as bleeding, symptoms in cycles and findings of medical examinations confirmed a medical problem. The endometriosis influenced the self from feeling extremely exposed and in need of help, feelings of worthless and guilt to feeling strong and capable of managing difficulties on one's own.

“Dependence” was the category of women’s experience when dependent on health care and significant others. The encounters with health care included confidence, understanding and empowering but also disappointment, mistrust, humiliation and even assault. Medical treatment for endometriosis was sometimes helpful, but severe side effects could also make the women worry about the future or force them to stop medication. Workmates and significant others were important for easing the negative influence of endometriosis on activity and participation.

In the third category, “A ruined life”, the women felt that life was ruled by the endometriosis, thus inducing sorrow and losses. This was described in terms of physical limitations and pain, which reduced the possibility for sexual intercourse, shared activity with significant others or fulltime work. Social relations were negatively affected and an existential grief was expressed when the women talked about their interrupted plans for living.

The core category “Surviving painful endometriosis”, represents women’s experience, emotions and the strategies they had to adopt to survive painful endometriosis and its treatment. This struggle for coherence, included finding understanding of the disease and its consequences, fruitful coping strategies and meaning in suffering. Knowledge of the condition was crucial to finding self-esteem as a women with a chronic disease but not one who was abnormal. This, together with helpful health care and significant others, facilitated successful coping strategies. The wish to help other women with endometriosis was a source of meaningfulness in grief in their life ruled by the condition.

Table 9. The categories with examples of properties and dimensions

Core category	Properties		Dimensions	
Surviving painful endometriosis Struggle for coherence	Understanding	Questions	↔	Understanding relationship
	Coping	Chaos	↔	Planning and control
	Meaning	Meaningless suffering	↔	Make difference
Categories				
A ruined life Endometriosis rules	Physical	Limitations	↔	Struggle
		Painful intercourse	↔	Sex and intimacy alternatives
	Work and career	Missed education	↔	Struggle for education
		Sick leave	↔	Struggle for work
	Social interactions	Broken partnership	↔	Maturity of relation
		Families' difficulty to understand	↔	Security in family
		Loneliness	↔	Really good friends
	Existential grief	Sorrow over childlessness	↔	Reconciliation
Dependence Help or harm	Encounters in health care	Humiliation	↔	Support
		Indifference	↔	Commitment
	Treatment by health care	Harm	↔	Relief
	Support from significant others	Suspicion	↔	Understanding
		Inhibition	↔	Support
Woman with painful endometriosis "I am different"	Body	Fear	↔	Obvious
		Strangeness	↔	Elucidation
		Indescribable pain	↔	Dull ache
		Copious bleeding	↔	Prevented bleeding
	Self	Fatigue	↔	Strength
		Exposure, helplessness	↔	Strength
		Reticence	↔	Openness
		Guilt over affecting others	↔	Governor endometriosis
		Victim of endometriosis	↔	Own responsibility

7 DISCUSSION

The main findings reported in this thesis are the considerable suffering which patients with chronic pain show when referred to a pain clinic, and the improvements which could arise in the follow-up of different treatment modalities. Patients' experience includes a process of possible change from a life in chaos to a life that works, facilitated by their own understanding, treatments and supported by health-care and significant others. Despite improvement, the persisting problems point at the chronicity of the pain condition. A congruent picture was developed from the patients' interviews and validated questionnaires.

7.1 GENERAL DISCUSSION

7.1.1 The burden of chronic pain

Different aspects of living in patients with chronic pain at a pain clinic are described in this project. In the qualitative studies (Studies I and III) the informants described their lives when referred to a pain clinic as ruled by pain. They lived with a constant struggle against overwhelming pain, connected, troublesome conditions, limited activity that influenced their families, work and social life. Informants with painful endometriosis illustrate the influence of the condition as: *"But things aren't the slightest bit like they were supposed to be, kind of. This disease ruined **everything**"* (Study III). Moreover, this poor quality of life was connected with mainly negative experience of health care.

In study II, validated and established instruments were used to collect data about patients' pain, related symptoms and HRQoL. The data were analysed in three clinically based treatment groups. A very low EQ-5D Index at base line was found in all patients (EQ-5D Index md 0.157), with extremely low values (-0.005) in the patients needing MMR. These were lower than in earlier studies of patients in Swedish MMR (Alfoldi et al., 2014; Swedish Quality Registry for Pain Rehabilitation, [SQR], 2016). The CPT-group had a significantly higher level in EQ-5D and SOC and lower levels in HADS and ISI than the MMR-group. Still, their condition represented reduced HRQoL, sleep disorders and some anxiety. For comparison, in a Swedish survey the EQ-5D Index in the normal population ranges between 0.7 and 0.9, depending on age. In individuals with different diseases such as asthma, diabetes or angina, the problems ranged between 0.66 and 0.79 (Burstrom, Johannesson, & Diderichsen, 2001).

The congruent findings, obtained by different designs, show a holistic picture of the suffering of patients in need of treatment at a pain clinic. The project confirms earlier research using

quantitative and qualitative methods (Lotte Nygaard Andersen et al., 2014; Breivik et al., 2006; Löfgren et al., 2016). The present studies were performed with one group of patients and this adds deepened understanding of patients' views.

7.1.2 Assessment at the pain clinic

To assess the patient's need and plan appropriate treatment is crucial and in units with different treatment alternatives this is of particular interest. The comprehensive MMR should be reserved for patients with complex pain problems (Kamper et al., 2014; SBU, 2010). The clinic in question performed the assessment in several steps. After the preliminary judging of the referral, the biopsychosocial pain analysis was done by one physician or, for patients with complex problems, by all the members of the interdisciplinary team.

The MMR-group's more severe state was represented in several PROM, pain duration and number of pain sites. Compared to the CPT-group, they were significantly younger, female, and represented lower SOC; but there were no differences in education or country of origin. Together this indicates an appropriate selection for MMR. The risk of selection bias in favour of higher education has been identified in women in MMR (Hammarstrom et al., 2014). This can be discussed in the light of the expected treatment outcome, where higher education is associated with better treatment benefit, pointing at the need for adapted treatment possibilities (Haase, Kuhnt, & Klimczyk, 2012; Dennis C. Turk & Rudy, 1990). To insure equality, the problems of selection bias should be addressed and studied further in patients with chronic pain (Hammarstrom et al., 2016; Haukenes, Hensing, Stålnacke, & Hammarstrom, 2015). Demographic variables and most PROM were equal in the CPT- and AO-groups at baseline (Paper III). Thus, patients with treatment at the pain clinic showed more insomnia, indicating some extended need, but still leaving questions about the assessment process and reasons for selection. Comprehensive, interdisciplinary assessment, is important, not only for establishing the patients' rehabilitation plan but also for alleviating pain and its related symptoms in the long term (Bileviciute-Ljungar & Norrefalk, 2014; D. Merrick, Sundelin, & Stålnacke, 2012; Pietila Holmner, Fahlstrom, & Nordstrom, 2013). The impact of assessment by a single professional has not yet been well studied quantitatively.

The patient's view of the first meeting was described in the interviews when the importance of the expert, understanding and committed meeting with health-care staff was the basis for the patient to get confirmation of the disease and start her or his understanding. This was needed to start the change process or induce coherence. There are similar findings from qualitative research at different health-care levels (Löfgren et al., 2016).

7.1.3 The situation at follow-up

In the one year follow-up, statistically significant improvements in HRQoL, insomnia, disability and kinesiophobia were shown in both treatment groups. The CPT-group improved also in pain intensity. These results must be seen with the pain problems at baseline in mind. The MMR-group showed a more complex pain condition than the CPT-group, but there was no statistical difference in pain intensity between them. It is concluded that pain reduction is possible for patients with minor problems, but more difficult to reach in complex situations. The literature is not conclusive about the possibility of minimizing pain for patients with chronic pain conditions yet pain reduction is still the patient's primary goal (Daniel Merrick, 2012; SBU, 2006; SBU, 2010).

Patients in MMR showed improvement in the main outcome EQ-5D Index (52%). The measured proportion improving varied from 29% on VAS to 57% on ISI. This can be compared with the SQRP where 48% improved on the EQ-5D Index (SQRP, 2016). Some of our patients became worse, observed in the MMR-group as varying from ISI (5%), EQ-5D Index (10%) to HADS anxiety (29%). No worsening was reported on the HADS depression scale. These figures may be compared with data from the SQRP, where HADS anxiety worsened in 19% and depression in 17% in the one-year follow-up (SQRP, 2016).

In the CPT-group, the share of improvement varied from HADS depression (24%), HADS anxiety (30%), to VAS (39 %) and EQ-5D Index (41%). Worsening was observed from PDI (13%) to HADS depression (32%). The results show that the improvement is in line with other results and reflects possible outcomes using today's resources and available interventions. The patient's EQ-5D index in the follow-up reached the level of those with chronic diseases in Sweden (Burstrom et al., 2001). These observations together with the informants' interview descriptions of a life worth living, but still struggling with pain confirm the chronicity of the pain condition and the possible need for further support by health care.

The absence of improvement, or negative development, for some individuals is a well-known problem in studies of chronic pain treatment (Heiskanen et al., 2012; Meineche-Schmidt et al., 2012). Efforts have been made to find predictive variables for treatment outcome, and a systematic review concluded that in fibromyalgia depression at baseline seemed to predict a poorer outcome (de Rooij et al., 2013). In addition some specific personal trait, belief in fate, worse disability and pain might show importance for a better outcome (de Rooij et al., 2013; Nyberg, 2011). In the actual project associations between baseline PROM and increased EQ-5D index were explored. Associations between higher level of insomnia and increased EQ-5D index were found in the CPT-group. From a clinical point of view, the connections

between insomnia and QoL indicate that awareness of the insomnia problem during the assessment process and the treatment, including pharmacological, psychological and educational interventions, seems to be working. Further research is needed to clarify connections between patients' characteristics and treatment outcome and thus be able to adapt treatment to patients' need, or to select patient for appropriate treatment (de Rooij et al., 2013; Nyberg, 2011).

Limited treatment outcome or negative side-effects of pharmacological therapy were experienced by the informants in this project, prompting them to search for complementary help outside traditional health care. This is in line with earlier research where informants disappointed by health care and treatment outcome seek for alternatives (Löfgren & Norrbrink, 2012; Young et al., 2014). As most of the today's available treatment is based on medical and psychological interventions together with physical training, a more patient-centred care might benefit from extended treatment options. The use of cultural- (e.g. music or participation in cultural activity) or natural- (horticultural therapy) based interventions might be a way to help patients reach the turning point, when conventional MMR is not successful (Rydstad, Löfgren & Drakos, 2014; Verra et al., 2012). To date, there is very limited knowledge in this field, thus more and larger high-quality studies are needed.

In anticipation of more successful treatment, the patient has to integrate chronic pain in her or his living as described by our informants in study I and confirming the theory of integration of chronic pain (Deshaies & Hernandez, 2011). This theory was initially based on research with diabetes patients and describes how a person can integrate new life experience of illness into the self in a three-phase process (Hernandez, 1991). From the first phase where the patient has minimal knowledge of the illness, denies problems and has minimal integration, via the turning point to the third phase, termed the "science of one", where an integration of illness and personal self occurs (Hernandez, 1991). Our findings in women with endometriosis, can partly be recognized in the theory of integration. This might be related to endometriosis as an intermittent, recurrent problem, with better phases, to the usefulness of medical and surgical treatment or the design of our study. The informants' complex experience might have overshadowed a possible changing process undetected in our open-minded interviewing.

Studies of patients' experience of chronic pain with different underlying diseases show similarities and differences. In our study I, the informants represented mainly musculoskeletal pain, while study III included women with endometriosis. The conditions have in common the significant, negative influence of pain on living, limiting physical activity and social

contacts, the importance for legitimacy of getting a diagnosis and explaining the invisible pain. Further, patients have to find their own understanding, learning the use of conscious coping strategies for good quality of life. Specific for women with endometriosis is the chronic, underlying disease with, with problems some become visible during operation or bleedings, with the need for specialised care. The impact of double exposure to chronic conditions should be studied more, as it might also help our understanding of patients with e.g. diabetes and neuropathic pain.

The informants with endometriosis (Study III) described feelings of grief not found in study I, but in e.g. the theoretical frame of Furnes and Dysvik, where a movement between “relearning the world” and “adaption” is described in patients in chronic pain (Furnes & Dysvik, 2010). In their model, disruption of meaning and also increased meaning are subthemes important for the adaption process, concepts also found in study I. Our informants described their good life before getting pain as that of a strong self, capable of helping others. During the MMR the possibility to support fellow patients was a factor important to get “the penny dropped”. With respect to these findings, the concepts of grief and meaning in chronic pain should be studied more, as possibly important factors in the integration process of chronic pain, to improve knowledge in nursing theory and form the bases for interventions (Dysvik & Furnes, 2010).

In the analysis of study III, when defining the properties of the core category, we found traits in line with the components of the sense of coherence concept (Antonovsky, 1987). The informants showed a struggle for understanding the body and self, corresponding to Antonovsky’s concept of comprehensibility, a struggle for functioning coping strategies corresponding to manageability and a struggle for meaning in suffering corresponding to meaningfulness, thus helping the women to reach some level of health. The present findings partly confirm the sense of coherence concept though they include a struggle and not a state as expressed by Antonovsky. The SOC concept was developed several decades ago but still catches components crucial for health. However, a further development of the concept, taking into account today’s medical and social changes, might further adapt it to present conditions. To study the SOC concept deductively would be a way of getting more insights into its importance for e.g. women with endometriosis. The stability of the SOC scale has been explored and discussed extensively (Eriksson & Lindstrom, 2005; Lindblad, Sandelin, Petersson, Rohani, & Langius-Eklof, 2015). Studies using the SOC concept as a theoretical framework in qualitative research on pain are limited (L. N. Andersen et al., 2014). In our study II the SOC mean level in the endometriosis subgroup did not differ from that in the

CPT-group and there was no change in SOC (CPT-group) at the one-year follow-up. The statistical association of higher SOC and improved HRQoL was not strong enough to explain a better manageability of the chronic pain condition in the follow-up.

7.1.4 The significance of health-care professionals

The research question included the goal of uncovering factors important for patients to improve quality of life. In study I, the informants reported that, besides helpful treatments, significant others were important in getting “The penny dropped”, bringing about a change in which health-care staff were of major influence. This is in line with earlier reports where limitations in medical treatment of chronic pain were pronounced and the non-specific effects of treatment, such as attention from health-care providers, were emphasized (Jamison, 2011). Congruent, qualitative research shows evidence of the informants’ need for supportive, listening, well-grounded and collaborative health-care professionals (Hopayian & Notley, 2014; Löfgren et al., 2016; Young et al., 2014). Our studies (I and III) strengthen earlier research in the importance of getting a diagnosis as the first step for informants to feel legitimized vis-a-vis health care, significant others and the community. The delay in getting a diagnosis, which is a confirmed problem in women with endometriosis, is thus a considerable concern (Young et al., 2014). Taking part in the decision-making process as a further step in treatment is important for the informants and requires customized information and a permissive physician (Löfgren et al., 2016; Young et al., 2014). The theory of empowering encounters with health-care professionals meeting women with chronic pain as developed by Skuladottir & Halldorsdottir represents a theoretical model for understanding these connections (Skuladottir & Halldorsdottir, 2008). Competence, caring, connection and wisdom are needed to meet the women’s need to achieve a sense of control as a basis for remoralization, i.e. mentally and emotional strength for psychological wellbeing (Skuladottir & Halldorsdottir, 2008).

Qualitative research into chronic pain still points at the deficiencies for good encounters in health care (Hopayian & Notley, 2014; Löfgren et al., 2016; Young et al., 2014). In study I our informants described mostly negative experience in the phase of seeking for and struggling with pain. The harmful gynaecological examinations, inducing a feeling of abuse by health-care professionals and found in study III, has not been described in the literature of chronic pelvic pain. However, mild-to-severe abuse in health-care has been reported from Northern countries, pointing at the problem and the need for further research and interventions (Swahnberg et al., 2007; Wijma, Zbikowski, & Bruggemann, 2016).

7.2 METHODOLOGICAL CONSIDERATIONS

The experience of chronic pain and the significance of treatment is complex and thus suited to study with different methods. Detailed design considerations are also discussed in the four papers.

This project should be seen as a first attempt to study patients at a pain clinic. There is a lack of knowledge about pain clinics, pointing at the need for well-structured and valid studies to explore, evaluate and compare their work. Problems and limitations found in the present project can help to improve the designs of further studies. A limitation is that the first author was studying her own clinic. However, to ensure neutrality, the designs were discussed by all authors, representing experience of a wide area of national and international research and clinical work. The data for the qualitative studies was collected by the present author and her main supervisor, neither being involved in the informants' treatment. For study II, the person first meeting the patient at the pain clinic asked about participation. All staff who met a presumptive participant, checked inclusion/exclusion criteria and supervised included patients' completion of the questionnaires at baseline. The follow-up questionnaires were handled by the author and the research nurse from the Department of Anaesthesia and Intensive care. All findings were discussed with peers well experienced in patients in the studied areas, and these included nurse colleagues and midwives, specialists in algology and gynaecology, doctoral students and teachers.

Limitations to generalization of the results can arise as the data collection was limited to one single pain clinic. However the informants in the qualitative studies described encounters with different health-care settings, though the findings were not limited to the staff of the pain clinic. Rather, the results reflect the patient's comprehensive experience from health care before, during and after treatment at the present clinic. Congruent data could to advantage be collected in different pain clinics to increase our knowledge, and to compare and develop the work.

The different treatment groups (MMR, CPT and AO) in study II were heterogeneous regarding pain aetiology and mechanism and were not selected as controls. Instead they represented different complexities of pain problems where treatment was adapted to individual need. The project offers insights into clinical situations, but does not compare treatment alternatives. Pragmatic, observational designs have limitations in lack of control groups or randomizations. The complex clinical state of chronic pain is difficult to study by placebo, sham treatment or waiting lists, leaving the possibility of patients figuring as their

own controls (Gordh, 2013). Further pragmatic trials measuring effectiveness are important for illustrating the real-life world including comorbidity and the complexity of patients' conditions and thus shaping knowledge (Rowbotham et al., 2013). The combination of qualitative and quantitative methods might also be seen as strengthening the findings in this natural context (Malterud, 2001).

The decision to include women with painful endometriosis into study III was threefold. First, endometriosis represented a considerable proportion of diagnosis in women in the clinic, i.e. 13% in this project. Secondly, they usually receive an adapted CPT intervention and thirdly, there was a lack of knowledge about their experience of pain treatment (Young et al., 2014). The findings are important for understanding the endometriosis condition, but are not representative for the heterogeneous sample of patients in the CPT-group. Further studies of patients with different pain conditions treated with CPT are needed.

Very early on we performed a power calculation for the sample size in study II. It was based on a hypothesized change in EQ-5D Index but did not take into account the different treatment groups or the analysis of associations. As the project with its observational design developed, the sample sizes seemed appropriate at least for the MMR and CPT-groups. For the logistic regression analysis, there might have been too many independent variables and the samples might have been too limited for statistical significance in the MMR and AO-groups. The response rate in the one-year follow-up was 63% (MMR-group), 62% (CPT-group) and 56% (AO-group), in line with or better than studies in other pain clinics (Jensen et al., 2016; Meineche-Schmidt et al., 2012) but lower than in pain rehabilitation clinics (Daniel Merrick, 2012; SQRP, 2016). The drop-out analysis showed no differences between responders on both occasions and only baseline responders in the MMR-group. In paper III the drop-outs were younger than the responders. In the qualitative studies, also invited patients declined participation. Discussion with them gave insights into the reasons drop-outs gave. Some presumptive informants explained declination by lack of time, interest and in some case by disappointment with the pain clinic. Great responsibility lies on the clinicians and researcher to mobilize future research participants. The use of modern electronic approaches for data collection might minimize some of the problems particularly among younger participants.

To gather valid data regarding pain is associated with problems, as the condition is subjective and lacks objective measurement. Our intention was to study the patient's view and develop a holistic picture with qualitative and quantitative methods, meeting the need for differing epistemological understanding. PROM has problems as response shift or recall bias. We used

validated, widely-used instruments and questions from the SQRP (2010) allowing high external validity. The interviews can be interpreted as a sort of internal validation and the follow-up interviews due to theoretical sampling (Study III) as a test of reliability.

Data derived from patient records has limitations as the records are clinical tools, not formed for research and depending on the writer. This led to deficiencies in for example pain categories. The group categorization was done by the author, based on the information available in the record three months after inclusion. There being no external examiner, the categorization was discussed by the authors. Patient compliance with treatment is uncertain and difficult to measure. However, in the interviews we got information about, for example, the ambivalence towards pharmacological treatment and the usefulness of TENS. The use of questionnaires including patient's satisfaction with treatment would broaden the patients' reported view and data from official registries such as the National Drug Registry might give other valid information.

8 CONCLUSIONS

- Patient-reported outcome measures and patient interviews provide a congruent picture: patients with chronic pain, assessed at a pain clinic, showed significant and complex suffering which includes low quality of life due to pain, related health problems, disability and affected social relations.
- Patients treated with MMR had significantly worse states at baseline, compared to conventionally treated patients, indicating a correct selection.
- Patients undergoing minor or comprehensive interventions at the pain clinic showed improvement in health-related quality of life and diminished pain-related health problems in the follow-up and described a change to a better life.
- Despite improvements, ongoing problems remained, pointing at the chronicity of long-lasting pain.
- To live a well-functioning life with chronic pain is facilitated by understanding, use of functional coping strategies, support from significant others and health care, thus integrating the chronic condition.
- Painful endometriosis and its treatment is experienced as a complex struggle for coherence, composed of feelings of difference, dependence and loss.
- To restore patients' confidence in health-care and facilitate integration of the chronic pain condition, health-care professionals' knowledge, understanding and commitment are crucial.

9 IMPLICATIONS

Health-care professionals should in their meetings with patients in chronic pain be aware of the complex condition and the possibilities for the sufferer's improvement. In anticipation of a causal therapy, health-care staff should support the patient's integration of her or his chronic condition with knowledge, understanding and commitment. Interventions to strengthen the patient's integration process could for example be to use patient role models or to involve the patient's significant others in the treatment. Assessment and individually adopted treatment at pain clinics should be based on systematically collected information. The use of congruent PROM in different pain clinics would further allow their staffs to increase their pain-clinic knowledge in a wider context. To ensure that health-care chains work, teamwork and cooperation between different levels should be further developed. A new, supporting organisation for patients when released from specialist pain care might help patients to maintain functioning coping strategies and assist when pain problems worsen.

10 FUTURE RESEARCH

- Further systematic, valid and comparable data about pain clinics' patients and work should be collected.
- There is a need for increased knowledge about patient's experience of different pain conditions (i.e. visceral and neuropathic pain) and their treatment.
- Intervention studies to support patients in chronic pain in the long-term follow-up should be carried out, as should studies to support the process of integrating chronic pain in a patient-centred way.
- More knowledge is needed about health-care professionals' perspectives when meeting patients with different chronic-pain conditions, in different organisations and settings.

11 SVENSK SAMMANFATTNING

Bakgrund: Långvarig smärta är ett stort problem för individen som ofta följs av sömnsvärigheter, mental ohälsa, begränsningar i aktivitet som delaktighet och därmed försämrad livskvalitet. Smärtan beskrivs som oförutsägbar och dominerande över tillvaron och då den är osynlig så upplever den drabbade att inte bli trodd. Behandling för långvarig smärta i Sverige sker inom primärvården, på smärtkliniker och rehabiliteringsenheter. Trots att många patienter får vård vid smärtkliniker så är kunskapen kring smärtklinikernas patienter och behandlingarnas resultat begränsad. Patientgruppen är heterogen vad gäller smärtorsaker, mekanismer och problemkomplexitet. Relaterad till de lokala förutsättningarna kan behandlingen variera från enstaka medicinska insatser till omfattande multimodala interventioner. Trots behandling är en bot för långvarig smärta sällan möjlig och patienten kan tvingas leva med sitt tillstånd.

Syftet: Avhandlingens syfte var att studera patienter med långvarig smärta, deras smärtrelaterade problem och livskvalitet när de bedömdes på en smärtklinik samt olika behandlingars betydelse för hälsa, livskvalitet och livsföring över tid.

Metod och resultat: Studierna genomfördes vid en smärtklinik, där två patientanpassade behandlingsalternativ studerades samtidigt. Patienter med förhållandevis begränsade problem behandlades konventionellt, det vill säga framför allt farmakologiskt (Smb-gruppen). Patienter med komplex smärtproblematik deltog i en multimodal rehabilitering, där sammanhållna pedagogiska, fysioterapeutiska, psykologiska och farmakologiska interventioner utfördes av ett interdisciplinärt team (MMR-gruppen). **Studie I:** I denna studie intervjuades 13 kvinnor och en man, i åldrarna 23-77 år (medel 46) från MMR-gruppen ett år tidigare. En kvalitativ, framväxande design med innehållsanalys användes för datainsamling och -bearbetning. Analysen resulterade i huvudtemat "Förändring är möjlig" och fem tillhörande teman. Informanterna beskrev att de kunde hitta från "Ett liv styrd av smärta" till en vardag som var "Att leva och inte bara överleva". Förutsättningen för denna förändringsprocess var att "Polletten hade trillat ner", det vill säga informanterna såg sambanden, lärde sig strategier att minska smärta och hantera livet och upplevde stöd från vårdgivare och människor i sin omgivning. **Studie II:** I denna prospektiva observationsstudie inkluderades 318 patienter med smärta >3 månader. De svarade på validerade frågeformulär rörande hälsorelaterad livskvalitet (EQ-5D), smärtintensitet (VAS), ångest och depression (HADS), sömnproblem (ISI), smärtrelaterade funktionsbegränsningar (PDI), rörelserädsla (TSK) och känsla av

sammanhang (KASAM) vid första besöket på smärtkliniken samt ett år senare. Information avseende demografiska data, smärtdiagnoser och behandlingar hämtades från patientjournalerna. Datamaterialet analyserades utifrån behandlingsalternativen: MMR-gruppen (n=43) (Paper II); Smb-gruppen (n= 278), och patienter som enbart bedömdes men återremitterades med ett behandlingsförslag (Bed-gruppen, n= 47) (Paper III). Alla grupper visade en låg hälsorelaterad livskvalitet samt förekomst av andra smärtrelaterade problem vid nybesöket. Patienterna i MMR-gruppen visade större problemen jämfört med Smb-gruppen ($p < 0,05$). MMR-gruppen förbättrades signifikant i utfallsvariablerna, EQ-5D, ISI, PDI och TSK vid uppföljningen. Smb-gruppen förbättrades i samma områden och dessutom i VAS. Inga förändringar observerades i Bed-gruppen. Ett samband mellan större sömnproblem vid första besöket och ökning i EQ-5D vid uppföljningen observerades i Smb-gruppen. **Studie III:** I studien intervjuades 13 kvinnor med smärta relaterad till endometrios och som hade fått konventionell smärtbehandling. Sexton intervjuer (inklusive 3 uppföljningsintervjuer) analyserades enligt den grundade teorins metod. Kärnkategorin beskriver kvinnornas erfarenheter, känslor och strategier under rubriken "Att överleva smärtsam endometrios, att sträva efter för sammanhang". Kategorierna som ingår i teorin är: "Kvinnan med smärtsam endometrios - jag är annorlunda", "Beroende - hjälpsamma och ogynnsamma erfarenheter från sjukvården och medmänniskor" och "Ett missat liv - endometriosen som styr".

Slutsatser och betydelse för vården: En samstämmig bild från frågeformulär och intervjuer visar, att patienter som bedöms på en smärtklinik rapporterar komplexa smärtproblem med allvarliga konsekvenser för hälsa och livskvalitén. Selektionsprocessen för MMR verkar fungera och både omfattande samt mer begränsade interventioner leder till en ökad livskvalitet och ett fungerande liv för patienterna vid uppföljningen. De kvarstående problemen visar ändå på ett kroniskt tillstånd med möjligt följande vårdbehov. Ett välfungerande liv med långvarig smärta förutsätter att se sambanden, att använda medvetna hanterings strategier och att få stöd från medmänniskor. I väntan på mer framgångsrika, kausala behandlingar av långvarig smärta, så måste vårdgivare ta hänsyn till den komplexa situationen som patienterna befinner sig i och främja deras integrationsprocess genom kunskap, förståelse och engagemang. Systematisk kunskap om smärtklinikers arbete och resultat samt patienternas erfarenheter av långvarig smärta av olika etiologi behövs för att vården ska utvecklas.

12 ACKNOWLEDGEMENTS

My first thoughts go to the patients participating in the studies. Thank you for your willingness to spend time to fill in questionnaires and share your experience of living with chronic pain with me. I wish further to express my gratitude to all those who helped in this project at the Department of Anaesthesia and Intensive Care at Södersjukhuset; Karolinska Institutet, Department of Clinical Science and Education Södersjukhuset and the Section for Pain Rehabilitation at the Department of Rehabilitation Medicine, University Hospital, Danderyds sjukhus.

My greatest thanks go to my supervisors, who so generously shared their knowledge and supported me during several years.

Monika Löfgren, my dear main supervisor. You came into the project when things were uncertain but with your knowledge and enthusiasm you managed to make the project take form. You supported me with never-ending patience. I am grateful for our shared time in research work, congress participation and dedication to patients in pain. I still wonder how you could manage to sense whenever I was in need of a supporting message from you!

Britt-Marie Stålnacke, my excellent co-supervisor from Umeå, who has all possible knowledge from the wide field of pain medicine and rehabilitation medicine as well as scientific work and writing. Your persistent energy and your patience and forbearance are admirable!

Christer Svensén, my co-supervisor from the Department of Anaesthesia and Intensive Care at Södersjukhuset. I am so glad that you believed in me and my project from the beginning, supported me through these years and facilitated my way into science with your excellent experience of research.

Leena Jylli, my mentor from the Karolinska Institutet. We have known each other for more than two decades as nurses engaged in patients in pain. Whenever in need of personal support in my doctoral education you were there with the right questions or wise counsels to bring me back on track. Thank you!

Eva Bålfors-Franklin and **Anne Kierkegaard**, former and present heads of the Department of Anaesthesia and Intensive Care at Södersjukhuset. I am very grateful for your support of the project and for giving me the chance to study at doctoral level.

Eva Joelsson-Alm, the first PhD nurse at the Department. I would not have started this project without your inspiring curiosity and practical help. Your knowledge, be it of statistics, research or health-care questions was invaluable for me.

Thank you all my colleagues at the pain clinic. Those who shared several years of clinical work with me and those who helped during the data collection while being trained at our clinic. “The pain clinic family” existed only at Södersjukhuset!

Annika Bjurling, Sofia Paulsson, Anna Johansson and Camilla Svensson – you developed the inter-disciplinary team and the holistic view of patients in chronic pain at our pain clinic. Your knowledge and enthusiasm were of deep importance for me and for the patients in their suffering.

Srdjan Boljanovic, Johannes Jacks, Jan-Rickard Norrefalk, Carolina Pernskjöld and Gurley Björkman. I have learnt so much from you about pain and pain management in patients suffering both acute and chronic pain.

Physiotherapists and occupational therapists from the Hälsopoolen Rehabklinik and Södermalms Rehab Södra. You contributed with the essential parts of physical exercise and training in the rehabilitation programme and were vital parts of the rehabilitation team. Thank you for your engagement!

Karin Löfgren, Åsa Sthen, Bim Edberg and the other secretaries at the department as well as **Mona-Britt Divander**, research nurse. You helped me with the data collection, data entry and transcriptions. Karin, as the first person the patients met at the pain clinic, your warm welcome was of great importance to them!

Lina Benson and Hans Pettersson, statisticians at KI Södersjukhuset. Your knowledge of the difficult field of statistics, excellent pedagogics and patience were of substantial importance for me and the project.

Tim Crosfield, the wonderful English linguistic reviewer. I have learnt so much from you about the English way of thinking and our discussions were always a great pleasure for me.

My doctoral education would not have been completed without the meetings with doctoral students including as **Helena Sjölin, Maria Cronhjort and Gisela Vogel**. You were important persons diving into science and sharing ups and downs in this exciting plunge.

My friends and family, I have to thank you so much for the never-ending support and patience you have given me, when the project took possession of all my mind.

Helena Röhss and **Marketta Kulju-Guevara**, I can't count the hours we spent Nordic walking together. All kinds of important subject were discussed and many questions got an answer! Thank you Helena also for your help with English language issues!

Claudia Biri and **Maja Robino** my Swiss friends and nursing colleagues, who were interested in my work and shared pleasure and anxiety during the project with me.

Susanne Steiner, my sensible sister who helps in all situations in life, by telephone or with her hands!

Sigrid Hållstam, your world is dancing, and joy for people, mine the world of pain and health care. Most important is to do something for humans and to develop oneself.

Semir Džoklo, you have supported me during the six years with never-ending patience. Thank you for taking me as I am, spending a lot of time in the bunker.

The project was supported by grants from:

The Scandinavian Association for the Study of Pain

Stiftelsen Tornspiran

The Stockholm County Council Fund for Care and Development

The Swedish Association of Health Professionals

Swedish nurses with special interest in pain (SSOS)

The Swedish Pain Society

The Swedish Society of Medicine

The Swedish Society of Nursing

Departmental grants from the pain clinic at Södersjukhuset

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