

Tapio Ojala

# The Essence of the Experience of Chronic Pain

## A Phenomenological Study



STUDIES IN SPORT, PHYSICAL EDUCATION AND HEALTH 217

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A Phenomenological Study

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UNIVERSITY OF JYVÄSKYLÄ

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## ABSTRACT

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Finnish summary

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Chronic pain is a complex combination of biopsychosocial symptoms affecting each other. In chronic pain, the patient's entire body may become a source of pain, and eventually the pain occupies the patient's mind and entire life. The purpose of this thesis was to search for a more profound understanding of the phenomenon of chronic pain from the perspective of persons with chronic pain and who have been treated for their chronic pain.

Thirty-four participants with different types chronic pain were interviewed. The transcribed interviews were analysed using Giorgi's phenomenological method consisting of four phases: (1) reading the transcriptions several times, (2) discriminating meaning units, (3) collecting meaning units into groups, into meaning structures, (4) the synthesis, describing the phenomenon of chronic pain.

The results indicate that chronic pain impaired the participants' life by controlling thoughts and making life itself painful. The strongest arguments made by the participants due to chronic pain were distress, loneliness, lost identity, and low quality of life. The participants stated that the key to managing their pain was to reconsider their meanings of pain. In the analysis, four essential themes of chronic pain emerged, namely: "Chronic pain affects the whole person", "Invisibility of chronic pain", "Negative meaning of chronic pain", and "Dominance of chronic pain".

Chronic pain is a multidimensional illness which requires a multidisciplinary approach to understand the phenomenon of it. Accordingly, a multidisciplinary rehabilitation programme is required to manage it; unfortunately the opposite is true in clinical practice, adopting only a rhetoric approach. A potential source of psychosocial symptoms may be the personal responses to the experience of chronic pain based on individual meaning. Thus, the focus should be to identify and revise the meanings of pain in order to manage chronic pain and to restore positivity in personal life. The phenomenological framework provides a relevant new insight into the present understanding of chronic pain.

Keywords: behaviour, chronic pain, disease management, education, life change events, quality of life, qualitative research

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This thesis is my exploration into chronic pain which started almost 20 years ago after graduating as a manual therapist. I attended many international pain conferences and courses, but chronic pain still remained a mystery to me. Pain was always defined as a sensory reaction to an underlying disease, reflecting the traditional understanding of pain. In short, my preliminary conception of pain was that there is a dysfunction or other abnormality behind the sensation of pain which needs to be identified, and normalizing the physical impairment would abolish the pain. However, strengthening weak muscles, stretching tight muscles, home exercise, manipulation, or mobilization relieved my clients' pain only for a short time, if at all. I cannot remember that pain was ever defined as an experience.

In physiotherapy training we were taught that a human being is a biopsychosocial unity, but we were not taught or I did not understand what it meant in clinical practice, i.e., how a physiotherapist can help psychosocially a patient with chronic pain. The mental suffering of many of my clients was more distinct than their physical dysfunctions but I could not help them because I was not familiar with the relation between pain and mind. A sense of helplessness, particularly in cases where I could not find any significant abnormality, prompted me to expand my understanding of chronic pain into other research fields. As a manual therapist, I had a large repertoire of manual skills but I had poor resources for encountering my clients and their pain as a lived experience.

Studying cognitive psychotherapy was an awakening for me, making me realize that a proper dialogue is one determinant of the success of a therapy. I hope that conversational training will someday have a better status in physiotherapy because it is the best method to find out what a patient with chronic pain thinks about his/her pain, i.e., the individual meanings of pain.

This thesis is also my exploration into myself as a human being and novice researcher. Scientific writing has been claimed to be "boring", but in my opinion, academic writing needs personality. The writer puts himself/herself into the text and, more importantly, there is a story to tell instead of a theory, results, and their interpretations. Thus, writing the thesis was more than a literary project; it was a genuine flow experience.

I would like to thank my supervisors Arja Piirainen, PhD, and Timo Laine, PhD, whose patience and encouragement were crucial in the analysis and the writing. Your methodological expertise and phenomenological thinking were something that I cannot thank you enough for. Professor Arja Häkkinen always had time for discussions by asking critical questions to improve the scientific quality of the thesis. I am very grateful to all of you.

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qualitative research support group and a source of inspiration through my academic career. The reviewers, professors Jennifer Bullington and Juha Perttula, I thank you for your positive comments. Like both of you, I believe that pain research needs this kind of approach to gain a deeper understanding of chronic pain. I would also like to thank all the participants who voluntarily told their stories about the experience of chronic pain. I also hope that this thesis provides new insight for pain clinicians to understand chronic pain more deeply and to apply better instruments in practice.

I am grateful for the financial support that I have received from several funding agencies. This work has been financially supported by personal grants from The Finnish Association for the Study of Pain, Oulu University Hospital Clinic of Physical and Rehabilitation Medicine, The Cancer Society of Northern Finland, and Suomen Ortopedisen Manuaalisen Terapian Yhdistys ry. Finally, I thank you Anna for editing this into academic English.

Most of all I would like to thank my family who have let me find my own life path. And Riitta-Liisa, my dearest wife, thank you for giving me the best years of my life. From now on I do not have “pop into the office to write a couple of words”. Now we have time to enjoy life together.

To the memory of my father.

Oulu, January 2015

Tapsa

## LIST OF ORIGINAL PUBLICATIONS

This thesis is based on the following publications, which will be referred to in the text by their Roman numerals I-IV:

- I Ojala, T., Häkkinen, A., Karppinen, J., Sipilä, K., Suutama, T., Piirainen, A., 2015. Chronic pain affects the whole person - A phenomenological study. *Disability & Rehabilitation* 37:363-371.
- II Ojala, T., Häkkinen, A., Karppinen, J., Sipilä, K., Suutama, T., Piirainen, A., 2014. The dominance of chronic pain - A phenomenological study. *Musculoskeletal Care* 12:141-149.
- III Ojala, T., Häkkinen, A., Karppinen, J., Sipilä, K., Suutama, T., Piirainen, A., 2015. Although unseen, chronic pain is real - A phenomenological study. *Scandinavian Journal of Pain* 6:33-40.
- IV Ojala, T., Häkkinen, A., Karppinen, J., Sipilä, K., Suutama, T., Piirainen, A., 2014. Revising the negative meaning of chronic pain - A phenomenological study. *Chronic Illness* Oct 20. pii: 1742395314555236. [Epub ahead of print]

## ABBREVIATIONS

ACC	anterior cingulate cortex
ACT	Acceptance and Commitment Therapy
CCBT	Contextual Cognitive-Behavioural Therapy
CIPA	Congenital Insensitivity to Pain
COX-2	cyclooxygenases
CP	chronic pain
CPAQ	Chronic Pain Acceptance Questionnaire
DIDY	didynamic nerve stimulation
e.g.	exempli gratia
fMRI	functional Magnetic Resonance Imaging
GWAS	genome-wide association studies
HCPs	health care providers
IASP	International Association for the Study of Pain
ICD-10	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
i.e.	id est, that is
IF	interferential nerve stimulation
LBP	low back pain
MCC	mid cingulate cortex
MRI	Magnetic Resonance Imaging
NSAIDs	non-steroidal anti-inflammatory drugs
PAG	periaqueductal grey area
PEMF	Pulsed Electromagnetic Field Therapy
PFC	prefrontal cortex
RCT	randomized controlled trial
rMS	repetitive magnetic stimulation
TENS	transcutaneous electrical nerve stimulation
TMS	transcranial magnetic stimulation
VAS	Visual Analogue Scale
WHO	World Health Organization

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# 1 INTRODUCTION

Chronic pain is a common world-wide problem. It has been estimated that one of every five persons experiences some type of chronic pain, and chronic pain accounts for more than two-thirds of all visits to physicians (Gatchel et al. 2007). A person with chronic pain may have physical implications, such as disabilities and restrictions in movements, and psychological implications, e.g., distress, anxiety, and depression (Linton 2005). Additional consequences of chronic pain may be a loss of identity and social isolation (Thomas 2000; Clarke & Iphofen 2008; Bullington 2009). Thus, chronic pain is very challenging to treat due to the fact that it is not only a pain but also a changed life situation which needs to be cared for. This leads to the conclusion that experience chronic pain is individual, as well as a strategy for consistent treatment in order to adjust to it (IASP 2012).

Chronic pain can be defined as a negative emotional experience that is affected by a variety of psychological factors through different inhibitory systems (Apkarian et al. 2011). As an experience, chronic pain first affects one part of the body and then gradually expands to the entire sphere of consciousness, eclipsing everything else in the mind (Morley 2008). Eventually, chronic pain has a negative impact on the mind, where negativity is the opposite of positive, regarding the consequences of pain and its aversive sensation, defined as a strong dislike or disinclination. The sensation of pain is always unpleasant because that is the nature of pain (Scarry 1985; Jackson 2000), but sensation of pain is not experience of pain (Sim & Waterfield 1997), which is an alternative insight into the traditional understanding of pain.

Other traditions where pain is associated as something negative include Christian religion, where pain may be understood as a result of sin (Linton 2005), and medicalization, which has changed our cultural attitude to a fear of pain, where pain must be abolished immediately (Buytendijk 1973). As a result, we may today have less tolerance to discomforts than before (Dahl & Lundgren 2006). However, pain is a normal life event and it has an important protective role (Vetlesen 2010). For example, CIPA, Congenital Insensitivity to Pain with Anhidrosis, is a genetic illness which leads to death in early childhood because of inability to feel pain (Sztriha et al. 2001).

At present, there is increasing evidence of the effects of chronic pain, but the phenomenon of chronic pain is still poorly understood (Apkarian et al. 2009; IASP 2012; Sessle 2012; Gordh 2013), which is reflected in poor management of chronic pain. Only a small minority of patients with chronic pain have attended a pain specialist and most of them are treated improperly (Breivik et al. 2006).

One potential reason for the present trend may be that despite that pain is multidimensional and requires multidisciplinary treatment (IASP 2012), most of the pain studies are from the medical perspective (Jackson 2000; Steinhaug 2007) where the patient experiencing the pain and the close ones, i.e., the intimate society, those who share life with the patient with chronic pain, are neglected. Moreover, natural science relies on perceptual evidence, which may be absent in chronic conditions, and because pain is an experience, a physical source for an experience may be difficult to identify (Apkarian et al. 2009; IASP 2012). Therefore, the purpose of this thesis was to search for a more profound understanding of the phenomenon of chronic pain from the perspective of persons with chronic pain and who have been treated for their chronic pain.



## 2 THE DEFINITION OF PAIN

The word “pain” is originally a Greek word, which came into English from the Latin word “poena” meaning punishment. Pain typically has a negative meaning, related to its negative physical implications, for example disabilities and restrictions in moving, and its psychological implications, such as depression and distress (Linton 2005; Morley 2008). On the other hand, pain belongs to life and life without pain would be unthinkable (Vetlesen 2010). In addition, pain teaches us how unfree, transitory, and helpless we are, and how life is essentially capable of becoming an enemy to itself (Buytendijk 1973).

The official definition of pain by the IASP, International Association for the Study of Pain, states that pain is *“an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage... it is also always unpleasant and therefore also an emotional experience... pain is always subjective”* (IASP 2012). Buytendijk (1973) claims that pain is a state of mind and therefore cannot be recalled, nor it can be anticipated; it can be experienced and can only be avoided by getting rid of its cause. Additionally, it can be stated that chronic pain is an illness reflecting how one responds to symptoms or disabilities rather than a disease with objective biological, structural or physiological changes (Breivik et al. 2006; Gatchel et al. 2007), manifesting learning and memory processes, and it may lead to maladaptive structural and functional brain changes accompanied by possible changes in body perception (Flor 2012), and it is typically expressed in a behavioural manner (Linton 2005; Morley 2008).

Nay & Fetherstonhaugh (2012) use the traditional definition of pain which was first used by McCaffrey (1968): “Whatever the experiencing person says, existing whenever the person says it does”. However, the authors suggest that despite pain being an individual experience involving, e.g., shock, unpleasant to unbearable sensations, humiliation, redefinition of the self and loss of function pain is also a life experience, including culture, religion, and other aspects of our being influencing how we interpret pain and cope with it. Therefore, Breivik et al. (2006) consider chronic pain as an illness in its own right; chronic pain is like any other chronic condition.

Taken together, this means that pain is mostly a mental state, an experience, without any difference between a mental or physical pain, only a complete individual experience. Thus, it is a myth that pain is an unambiguous signal of tissue damage leading to disability and that the experience of pain can be treated only by medical interventions (Crombez et al. 2012). In physiotherapy, there are a number of other myths of pain, for example, "low back pain is a benign, self-limiting condition", "all back pain patients are alike", "let pain be your guide", "acute and chronic pain are similar", and "no pain no gain" (Liebenson 2012).

## 2.1 Epidemiology of chronic pain

Chronic pain touches many of us. It has been estimated that 12-30% of the population have some kind of chronic pain (Breivik et al. 2006; Schopflocher et al. 2011). In back disorders, pain is the most common indication for seeking treatment (Waddell 2004; Koho 2006), and the prevalence of chronic musculoskeletal pain varies from 4% to 13% (Mourao et al. 2010). The prevalence of moderate to severe chronic pain is 19% for all adults in Europe, as it is also in Finland (Breivik et al. 2006). The annual costs for chronic pain in Finland are € 600 million, one third of which is for examination, treatment, and rehabilitation and two thirds for compensation of disablement (Pohjalainen & Karjalainen 2008).

The traditional clinical classification of back pain is acute, recurrent, and chronic, but epidemiologically pain can be classified as recurrent, intermittent, and episodic. A pattern of back pain over a longer period of time - total days of pain in one year - is a better clinical concept. Therefore, the prevalence of back pain may vary depending on the interval reported. One-month prevalence varies from 19% to 43%, and lifetime prevalence may vary from 60% to 70% (Nachmeson et al. 2000).

Despite the advances in technology and numerous pain studies the rate of disability due to chronic back pain and other chronic health conditions has increased during the last decades, and it is estimated that they will increase in the future (Deyo et al. 2009; WHO 2012). In his review, Sessle (2012) calls chronic pain a "silent epidemic", meaning that there is too little awareness of the real prevalence of chronic pain and nobody can count the costs of reduced quality of life, negative impact on relationships, job loss, ineffective management of pain, and increased rates of depression.

## 2.2 Aetiology of chronic pain

The aetiology of chronic pain is not fully understood, and unlike acute pain, it does not have a protective role by warning of bodily harm (Winterrowd et al.

2003; Linton 2005). There is general agreement that chronic pain is a multifactorial experience which is affected by biological, physiological, psychological, social, and contextual factors (Linton 2005; Gatchel et al. 2007; Nay & Fetherstonhaugh 2012; IASP 2014).

The pathophysiology of chronic pain can be divided into two features: (a) nociceptive pain of musculoskeletal origin and (b) neuropathic pain from neural structures. These features can be in isolation or combination (Mackintosh & Elson 2008). There is evidence that 20% of acute pain may transition into chronic pain if it is not treated properly (Lynch et al. 2008).

A large European survey (Breivik et al. 2006) found that the most common causes of chronic pain were osteoarthritis and rheumatoid arthritis. These were followed by deteriorated or herniated discs, degeneration or fracture of spine, trauma or surgery, and migraine. In the survey, for 12% of the participants the cause of chronic pain was unknown. This is very common in chronic pain which may have several aetiologies and can be caused by a number of different factors, such as injuries, diseases, pathology, and medical procedures.

### **2.2.1 Genetic factors**

The aetiology of chronic pain is understood to some extent as being a physical trauma, occupational, or related to psychological aspects such as distress (Gupta et al. 2007), but it is unclear why some individuals develop chronic pain while some do not and why pain persists only in some individuals. An answer for this has also been sought in a genetic vulnerability to pain.

In a review by Gatchel et al. (2007) the authors explain how the genes affect pain as biological functioning which is dependent on overexpression or elimination of a gene resulting in functional changes of a system or an organ. Put briefly, gene expression can modulate the individual sensitivity to pain. In the future, it may be possible to turn a single gene on or off to relieve pain.

In a recent review by Holliday & McBeth (2011) it was concluded that genetic factors increase the risk for chronic pain which is independent of the site of pain. However, genome-wide association studies (GWAS) have a limited impact on the understanding of the genetic basis of chronic pain; for example, migraine is found to be genetic whereas fibromyalgia is still poorly defined. Taken together, the authors state that there is evidence for genetic factors for chronic pain but a lot of work remains ahead.

### **2.2.2 The brain and chronic pain**

The pathogenesis of chronic pain is in most cases unknown (Gordh 2013). Technological advances in magnetic resonance imaging (MRI) and functional MRI (fMRI) pain studies in the 1990s enabled imaging of brain functioning. This might be one of the reasons for the concentration on the brain in pain research at present. Enhanced signal detection in neuroimaging is an indirect method to evaluate neuronal activity, based on the neurovascular coupling between neuronal activity and hemodynamic response (Davis 2011). Most of the studies

are still done with healthy subjects, while many questions for acute pain, and particularly for chronic pain, have remained unanswered. The fundamental conclusion is that there is no a pain centre in the brain (Apkarian et al. 2011), and in chronic pain the brain is not functioning normally; chronic pain being reminiscent of other neurological conditions associated with cognitive impairments and behavioural alterations (Baliki et al. 2008). Furthermore, the reduction in grey matter may cause an increased perception of pain associated with, e.g., memory and cognitive deficits (Davis 2011).

Chronic pain is a state where the brain itself can activate pain perception without any external stimulation (Apkarian et al. 2011). Brain areas that are active in pain processing in the Neuromatrix of Pain (Figure 1) include the primary and secondary somatosensory cortices (S1, S2), mid cingulate cortex (MCC), insula, thalamus, anterior cingulate cortex (ACC), prefrontal cortex (PFC), basal ganglia, cerebellum, and the brain stem region, particularly periaqueductal grey area (PAG), which are active also in non-nociceptive perception, such as attention, decision-making, motor function, and affective reactions and display a wide range of individual differences.

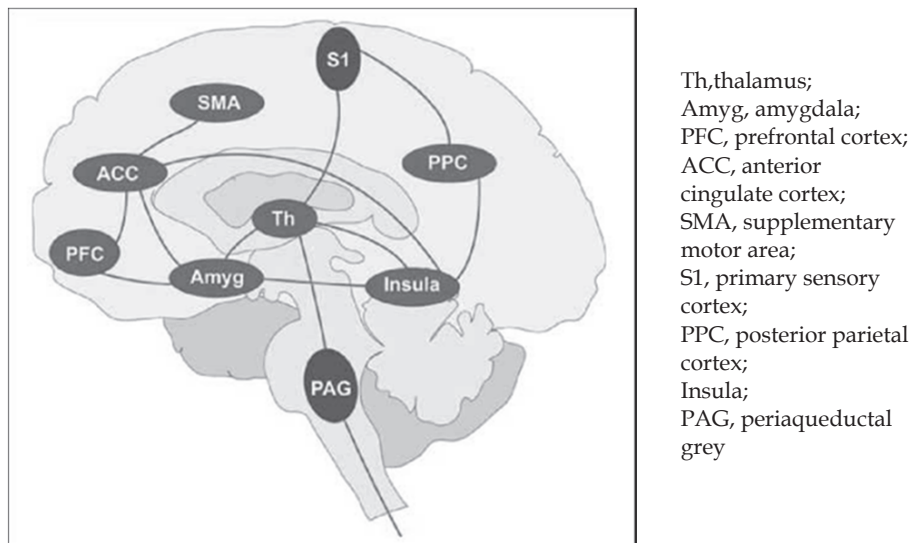


FIGURE 1 The Neuromatrix of Pain.  
(<http://humanantigravitiesuit.blogspot.fi/2013/06/melzack-and-katz-part-6c-history-of.html>).

Before brain imaging can predict or diagnose pain there are, for example, technical, statistical, and neurophysiological considerations that limit the ability to apply neuroimaging to identify a pain biomarker or pain response in the brain of an individual. Neuroimaging responses to pain can vary in healthy individuals and by personal experience and can thus only truly be measured by self-report (Davis 2011).

A recent RCT (Randomized Controlled Trial) by Borckardt et al. (2011) found a promising analgesic effect for pain resulting from transcranial magnetic stimulation (TMS) to the prefrontal cortex. The effect is unclear, but they suggested that by acting through a cortically perceived control circuit regulating limbic and brainstem areas it may comprise an important part of a circuit of perceived controllability regarding pain, stress and learned helplessness.

Although chronic pain can change the structure and function of the brain the changes are to some extent reversible due to the plasticity of the brain. However, the individual differences in brain structure and function must be accounted for therapy where the focus is on the alteration of central pain memories and maladaptive body perception (Davis 2011; Flor 2012).

On the other hand, there is also evidence that the reverse, i.e., degeneration of the brain, can occur in chronic pain conditions. The brain of a patient with chronic pain is not simply a healthy brain processing pain information, but rather, it is altered by a persistent pain in a manner reminiscent of other neurological conditions (Baliki et al. 2008).

In a recent study by Wager et al. (2013) scientists were able to predict how much pain the participants felt by looking at the images of their brains. However, it should be kept in mind that sensation of pain is different than experience of pain; sensation is only a part of the experience. Brain imaging does not explain or visualize the experience of pain (Derbyshire 2011). Imaging the brain does not explicate the experience of pain because there are individual differences in pain-related brain function and structure due to both pre-existing vulnerabilities and disease-driven factors. Thus, it can be concluded that an image of the brain is not the experience of pain and brain imaging does not diagnose pain (Davis 2011).

### 3 THE BIOPSYCHOSOCIAL MODEL OF PAIN

Pain has been explored by different methods and different research fields, but medicine has dominance in pain research (Jackson 2000; Gatchel et al. 2007; Steinhaug 2007). Traditional biomedicine has its roots in natural science, which needs empirical evidence for the symptoms of pain, thus if no evidence can be detected the experience of pain cannot be explained (Apkarian et al. 2009) and the pain can then be considered as being of imaginary origin (Pesut & McDonald 2007).

The traditional biomedical view has often also been criticized for dualism, keeping social and psychological aspects apart from pain; this is also called the Cartesian legacy, referring to Rene Descartes' (1596-1650) notion of mind-body dualism. In fact, Descartes tried to explain the integration of psyche and soma in more depth, which can be summarized as following: pain is a bodily sensation which prevents more harm or damage and signifies an underlying pathology, and ethics require alleviating pain as much as possible (Duncan 2000). Despite advances, the traditional biomedical approach has its limitations, such as the following: (a) the intensity of pain is not proportional to the underlying damage, (b) recovery of the tissue damage does not necessarily abolish pain, and (c) the biomedical model does not account seriously for the influence of the psychological and social factors on the experience of pain (Keefe & France 1999). Therefore, a more complete understanding of pain was introduced, namely the Biopsychosocial Model, which is presented in Figure 2.

In his first article (1959) Engel described how a negative childhood with emotional and physical experiences may affect a person to become a "pain-prone patient" suffering from pain without any identified evidence. In 1977 Engel published an article in which he presented the Biopsychosocial Model of Pain where the emphasis in the assessment and therapy of pain are on the biological, psychological, and environmental factors. The model was widely accepted, partly due to the Gate Control Theory of Pain by Wall and Melzack (1965), but also due to the inability of biomedicine to explain and treat chronic conditions.

The problem with chronic pain is the lack of physical evidence for pain, which made it imperative to find alternative explanations. This led to a sophisticated model of the Gate Control Theory of Pain, the Neuromatrix of Pain (Figure 1), where pain is produced by the output of a widely distributed neural network in the brain (Melzack 2001, 2004; Moseley 2008). Related to the theory, there is a lot of evidence that psychosocial factors may be the main contributors in the progression and mode of chronic pain (Vlaeyen & Linton 2000, 2012; Main et al. 2001, 2008; Pincus 2004; Waddell 2004; Crombez et al. 2012), which contributed to the Biopsychosocial Model becoming the most complete paradigm to understand chronic pain (Waddell 2004; Linton 2005; Breivik et al. 2006; Gatchel et al. 2007; IASP 2012).

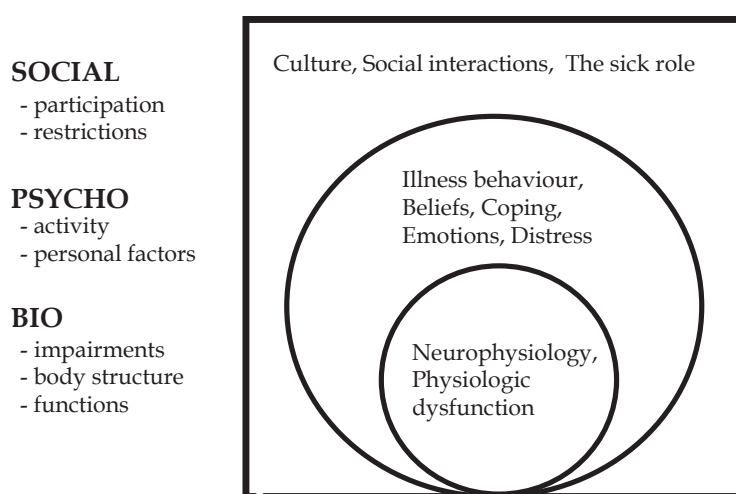


FIGURE 2 The Biopsychosocial Model (Waddell 2004).

The present understanding of the experience of chronic pain involves sensory, affective, cognitive, and evaluative dimensions (Figure 3), which should be taken into account in the assessment and treatment of chronic pain (Sim & Waterfield 1997; Sim & Smith 2004). The dimensions can also be regarded as the qualities of the experience of chronic pain which make it more difficult to detect and treat by traditional approaches. In addition, the experience of pain is cultural- and moral-dependent (Honkasalo 2000; Nay & Fetherstonhaugh 2012) including opinions and interpretations (Melzack 2001, 2004).

Biopsychosocial concepts have deepened our understanding of the effects of chronic pain. Thus, the utilization of the Biopsychosocial Model is suggested in chronic pain rehabilitation and accordingly, involvement of multidisciplinary rehabilitation methods, which have been shown to increase the number of work days, increase self-efficacy, and reduce health care consultations in patients with low back pain (Kool et al. 2005). In a review by George (2008), it was concluded that biopsychosocial therapy is more effective than individual



approach for chronic low back pain when pain reduction or improvement in function was measured.

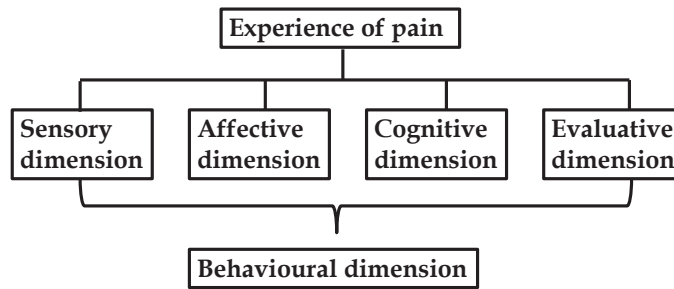


FIGURE 3 The characteristics of pain (Sim & Waterfield 1997; Sim & Smith 2004).

Despite its benefits, the Biopsychosocial Model has the following limitations: (a) it ignores the individuality in the experience of pain, (b) it does not explain the experience of pain and most importantly, (c) it ignores the meaning of the experience of pain, which can constitute, e.g., pain beliefs, fear of pain, emotions related to pain, attitude towards pain, cognitions of pain, and coping expectations. Moreover, due to the long history of natural science in pain research, pain is measured with a variety of indicators and classified into different categories.

### 3.1 Measuring pain

Because pain is invisible and immeasurable, its existence, quantity, and quality are difficult to detect (Jackson 2000; Melzack 2001, 2004; Clarke & Iphofen 2005, 2008; Turk & Winter 2010) thus; the only evidence of the existence of pain is based on the person's own report as a subjective experience (Lee & Tracey 2010). With the current instruments, it is challenging to examine pain directly, which is why indirect instruments are used, such as questionnaires, which refer to the consequences and effects of pain.

There are at least one hundred different kinds of questionnaires of pain categorized as questionnaires on pain related to illness, such as arthritis and cancer, to age, i.e., geriatric and paediatric patients, and structurally related pain, e.g., musculoskeletal, neuropathic pain, and psychological questionnaires (Wittink & Carr 2008). Each questionnaire has its own focus in relation to pain: for example, the Oswestry Low Back Pain Disability Index measures pain related disability, the Roland-Morris Disability Scale measures disability, the RAND-36 Health Survey measures quality of life, while CPAQ (Chronic Pain Acceptance Questionnaire) measures acceptance of pain.



Maybe the most often commonly used instrument in clinical practice is the VAS (Visual Analogue Scale), where the intensity of pain is rated by a number from 0 (no pain) to 10 (worst possible pain); however, VAS measures only the sensory dimension of pain - the intensity of sensation - not the experience of pain. In addition, its use for children and elderly is complicated because it requires cognitive, visual, and manual abilities (Harms-Ringdahl 2012). The same validity problem concerns the use of questionnaires with persons who have difficulties with communication or cognition, dementia or who are intubated or unconscious. In those cases, the use of other assessment methods is suggested, such as self-report and observation of patient behaviour (Herr et al. 2006).

### 3.2 Classifying pain

Pain does not have its own diagnosis, but is classified in many ways. The traditional anatomic definition is by structure (neuralgia), organ (heart), location (stomach), or by cause of pain (post-operative pain). Moreover, pain can be classified using a grouped scale as nociceptive, neuropathic or idiopathic pain (Vainio 2009). A common classification is done by using a temporal pattern, classifying pain as acute pain - duration less than three months - or chronic pain, which has lasted more than three months, which is also defined as pain that persists beyond the normal time of healing (Kalso et al. 2009).

Acute pain can be regarded as the body's normal response to tissue damage, such as a cut, an infection, or physical injuries. This type of pain usually has rapid onset and often remits in no more than a few weeks if treated properly. Chronic pain is difficult to treat because the cause can rarely be identified (IASP 2012). Generally, acute and chronic pain has very little in common despite the word "pain" (Apkarian et al. 2009) and acute pain can be regarded as life-protective whereas the purpose of chronic is obscure (Melzack 2004; Kalso et al. 2009).

IASP (2014) has classified chronic pain in the same way as diseases in the ICD-10 (International Classification of Diseases) taxonomy by classifying pain by aetiology, anatomy, organs, duration, and intensity. The taxonomy has five axes in which Axis 1 concerns the region of pain, Axis 2 the organ system, Axis 3 characteristics of the pain episode, Axis 4 integration of intensity and duration of pain, and Axis 5 deals with the aetiology of pain. These taxonomies are supposed to complement each other and help clinicians estimate a prognosis of pain, prevent risk factors and diseases, and they constitute a mutual vocabulary for communication and for diagnosing diseases (IASP 2014).

### 3.3 Disability and chronic pain

Disability has many definitions, but according to the WHO (World Health Organization, 2014) disabilities covers impairments, activity limitations, and participation restrictions. Waddell (2004) claims that chronic pain is often linked with disability due to restriction of movement. The assumption is that there is disability due to pain, but this may be a false conclusion. Although pain and disability often go together they are not the same. Pain is an experience while disability is restricted activity which is not necessarily caused by pain. Disability, like pain, is highly individual, and it is not about what the person is unable to do; it is about performance, not capacity. Saariaho (2012) concludes that disability is related to restrictions and limitations in daily living and can be attributed to pain. Therefore, treating pain does not always abolish disability and conversely, restoring function does not necessarily remit pain (Waddell 2004; Moseley 2008).

Disability is considered as a deviation and a disabled person is considered as abnormal. In rehabilitation, disabled persons are normally assisted to accept, adapt, or adjust to live with their impairment, but the important question is: who is to define what is normal? It has been found that persons with disabilities undergo conceptual transformation changing the way of their thinking about their disability, considering themselves as capable and competent persons (Whalley Hammel 2006).

In 2001, the WHO developed the International Classification of Functioning, Disability and Health (ICF) providing a framework for classifying the consequences of injuries and diseases. ICF is an attempt to acknowledge that people interact with their environments by personal factors which impact an individual's ability to act and participate. These include physical, social, cultural, economic, political, and legal contexts in which impairments are experienced (Whalley Hammel 2006). A modification of ICF was developed by Cieza et al. (2004) as the Core Sets and Comprehensive ICF Core Sets for different chronic conditions, but for some reason their implementation to clinical practice is rare.

A review by Stier-Jarmer et al. (2006) concluded that ICF implementation on chronic low back pain (LBP) was a promising new framework. In another review by Roe et al. (2013) the criticisms were towards psychosocial and environmental factors that were scarcely addressed. In addition, the implementation of ICF in practice is time-consuming and there is a need to have more commonly used measures for different patient-reported problems.

With reference to pain, ICF is problematic because pathology is the starting point in the ICF and the classification assumes that health status interacts with all levels of functioning (Sakari 2013). The major problem with ICF is that the fundament of it - pathology - may be absent in chronic pain. Logically in that case, there should not be any disability or impairment caused by pain because there should not be any pain.

Additionally, ICF does not acknowledge the word “experience” in the definition of pain but describes pain as a “sensation”, linking it to the era of the reign of biomedicine with pain being a symptom of a pathology, which needs to be found to acts as a guideline for treatment.

In ICF the relation between health status and pain, and more specifically, the relation between functioning and pain, particularly how the psychosocial factors are associated with pain, is not explained as was concluded by Roe et al. (2013). ICF presents pain in body parts, e.g., “low back pain”, which give the impression that it is the only appearance of pain. The basic principle of pain is being invisible, immeasurable, and individual, comprising sensory, affective, cognitive, and evaluative aspects, and the fact that it is an experience (e.g. Sim & Waterfield 1997; Clarke & Iphofen 2005, 2008; IASP 2012). It is questionable how pain can be categorized solidly, taking into account all the criteria of the experience of pain. The ICF presentation of pain is used in physiotherapy training, for example, but current version provides an inadequate understanding of pain.

ICF does not provide official diagnoses of pain for a patient. Medicine uses the IDC-10 taxonomy, which classifies pain predominately based on an identified pathology (IASP 2012), which has its own incompleteness regarding pain, but ICD-10 taxonomy is the only official reference for a diagnosis given for pain and other illnesses. Despite the limitations of ICF with reference to pain, it needs to be remembered that pain is a part of disability.

## 4 PSYCHOLOGICAL ASPECTS OF CHRONIC PAIN

There is a lot of evidence that the most common risk factors for chronic pain are psychological, also known as "yellow flags" (Sullivan et al. 2001; Waddell 2004; Jarvik et al. 2005; Linton 2005; Morley 2008). They are more powerful than traditional biomedical and ergonomic variables, such as tissue damage and amelioration of biomechanical dysfunction following injury. Level of distress and dysfunctional thoughts have been found to be important factors in the development of chronic pain (Main et al. 2001). Thus, as stated by (Kolt 2004) all physiotherapy interventions in chronic pain should include some psychological modalities.

Learning is a salient phrase in one of the latest understandings of chronic pain where implicit learning processes may change behaviour without the person knowing about it, being therefore difficult to extinguish. Implicit learning processes involve sensitization, operant and respondent conditioning, as well as priming and social learning which is commonly known as central sensitization. Another learning mechanism is the operant conditioning named pain behaviour, which is maintained by positive feedback, such as avoiding exercise that is followed by pain. In clinical practice this means extinguishing and relearning maladaptive memory processes (Flor 2012). As stated by Pincus (2004), pain behaviour is dependent on how a person believes he/she can or should change his/her behaviour where the beliefs in turn depend on the degree to which the person thinks he/she can control the pain and life in general. Furthermore, the presence or absence, and the degree of cognitions and beliefs about pain form the basis for the patient's emotional reactions, affective states, and thus, for pain behaviour (Eimer & Freeman 1998).

According to Pincus (2004), there are a number of characteristics of people that manifest in different kinds of behaviour, such as introvert, extrovert, and neurotic and so on. Responding emotionally to situations in life, e.g., to pain, justifies that personality affects the pain experience and interaction with others, how to elicit help from others, and how to impact the way others respond to one's response. There are multiple affective components of pain which are usually negative, such as fear, anger, and frustration, but there are also some

positive components, such as joy and happiness, but research on these is less clear and limited (West et al. 2012a). The primary emotions that can be found in chronic pain are distress, depression, fear-avoidance, catastrophizing, and self-efficacy (Main et al. 2001, 2008; Linton 2005; Morley 2008).

#### **4.1 Distress in chronic pain**

Distress is commonly observed in persons with chronic pain. It is an overt communication of pain, such as suffering, which can also modulate the experience of pain by amplifying or inhibiting the severity of pain (Gatchel et al. 2007). In chronic pain, depression and anxiety often coexist with psychological distress by affecting each other and predicting more relentless pain (McCaffrey et al. 2003).

It has been suggested that it is possible that emotional distress reactions to a painful situation may arise as a function of inaccurate pain expectancies (Sullivan et al. 2001) and people who are distressed at the first episodes of pain are more likely to become disabled (Pincus 2004). It has also been found that if a highly valued aspect of the self is trapped by pain it is associated with greater emotional distress (Morley 2008).

#### **4.2 Depression in chronic pain**

The prevalence of depression of patients with chronic pain varies from 5% to 100% (Gambassi 2009). Depression has been found to be more prevalent in patients with chronic pain than in normal population but in both cases it is poorly understood. Depression in chronic pain is associated with hopelessness, helplessness, and a feeling of being tortured or punished, and as a direct threat to integrity of the self. The link between depression and pain is not simply causal and straight forward; it seems that the presence of pain can result in the development of depression and the presence of depression can result in an increased risk of experience of pain, thus affecting each other (Pincus 2004).

In a study by Sullivan et al. (2001) it was concluded that depression was associated with the experience of heightened pain and emotional distress in response to a painful stimulus. Jarvik et al. (2005) concluded that the level of depression predicted the development of low back pain in three years. Depressive patients were 2.3 times more likely to report back pain than non-depressive patients. Depression was a stronger predictor of back pain than clinical or anatomical factors.

There is an ongoing debate if depression with chronic pain is similar to depression as a mental disorder, which has its own strict criteria, whereas in chronic pain depression is self-reported. Therefore, the reliability of assessing depression of patients with chronic pain has been questioned (Saariaho 2012).

The main difference is that people who have a mental disorder complain more about their mood whereas people in chronic pain complain more about their pain (Pincus 2004).

### **4.3 Fear-avoidance behaviour in chronic pain**

Fear is one of the common reactions to illness and injury, together with anxiety, sadness, and anger. These emotions affect physiological functioning and behaviour. Fear is an emotional reaction resulting from an immediate, real, and present threat and may be more disabling than pain itself. Fear and avoidance result from a behavioural pattern which is not equal to the underlying pathology, leading to an exaggerated experience of pain (Crombez et al. 1999, 2012). It has been shown that fear is one of the most potent predictors of disability and chronic pain, thus being a significant problem (Vlaeyen & Linton 2000). This in turn is a challenge to biomedicine, which often ignores psychosocial factors and focuses on structural abnormalities (Crombez et al. 2012).

Anxiety differs from fear in that anxiety is an emotion related to cognitive anticipation of a future undesired threat. Fear-avoidance is related to kinesiophobia as a fear of physical activity stemming from a belief that it will lead to pain. There can also be a fear of fearing, which appears, e.g., as avoidance of social activities which might be associated with an arousal of fear (Wiese-Bjornstal 2004). Avoidance is referred to as a learned behaviour which averts the aversive event. Learned behaviour occurs when the undesirable event has been successfully avoided by certain behaviour (Vlaeyen & Linton 2000).

The fear-avoidance behaviour presented in Figure 4 refers to the avoidance of movements based on fear. It is a central mechanism in the development of long-term back pain problems, particularly in deconditioning (Vlaeyen 1999; Vlaeyen & Linton 2000). The explanation is that in the short term, avoidance is protective, but in the long run it worsens the problem. Therefore, there is a need to take into account psychological and behavioural aspects in addition to cognitive aspects in pain assessment and therapy interventions (Vlaeyen & Linton 2012).

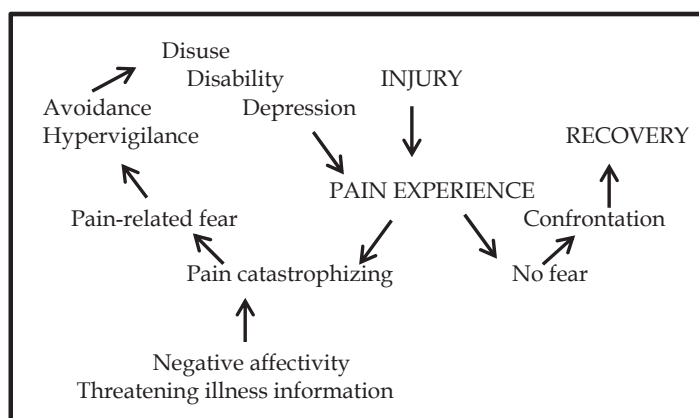


FIGURE 4 The fear-avoidance model (Vlaeyen 1999).

#### 4.4 Catastrophizing in chronic pain

Catastrophizing is a multidimensional construct comprising aspects, such as rumination, magnification, and helplessness (Sullivan et al. 2001). It is a general or specific cognitive style to physical symptoms including negative thoughts and self-statements about the present and the future (Pincus 2004).

It has been shown that catastrophizing is associated with the experience of heightened pain and emotional distress in response to painful stimuli (Sullivan et al. 2001). In addition, disability, poorer quality of life, vitality, mental health, and general health were significantly associated with pain catastrophizing (Lame et al. 2005). It has also been suggested that misinterpretation of pain - thinking of pain as a catastrophe, i.e., hypervigilance - as a serious injury or pathology without control may lead to an excessive fear of pain, avoiding physical activity, increasing deconditioning, thus worsening the problem (Crombez et al. 2012), as presented in Figure 4.

#### 4.5 Self-efficacy in chronic pain

The original concept of self-efficacy was introduced by Bandura (1977). It should be understood as coping and self-managing mechanisms, how a person believes he/she can cope with chronic pain. Self-efficacy is determined by motivation and it in turn is determined by adherence to cooperation with treatment (Pincus 2004).

A recent study by Craig et al. (2013) concluded that experiencing low self-efficacy elevated depressive mood and vice versa. Alternatively, chronic pain impacted self-efficacy, lowering the person's expectations and confidence in

being able to function as desired, which together contributed to depressive mood. Moreover, self-efficacy was found to be a strong predictor of disability, pain intensity, and avoidance behaviour (Meredith et al. 2006). Self-efficacy beliefs of controllability of pain may result in less intense pain, less unpleasant pain, with an increased tolerance of pain (Gatchel et al. 2007).

Conclusively, there is evidence that a variety of psychological symptoms are associated with pain, but the evidence does not explain whether pain is a cause or consequence of these symptoms, which can result in diagnostic errors and further application of ineffective treatments. The liveliest debate concerns depression and its association with pain. In addition, fear-avoidance and catastrophizing are related to each other and particularly the latter to the former by exaggerating it. In therapy, this means that affecting one symptom affects another either positively or, in the worst case, negatively, resulting in a more complex experience of pain. Therefore, dialogue including support and pain education to improve self-efficacy is a proper implementation and consequently, dialogue is one of the fundamentals which ultimately define the efficacy of therapy as a whole (Reynolds 2006).



## 5 TREATMENT OF CHRONIC PAIN

As stated, e.g., by IASP (2012), chronic pain is a multifactorial illness whose cause can be rarely identified, involving multiple psychosocial and physical consequences and an individual experience where responses are dependent on (a) culture, (b) past experiences, (c) other persons' opinions, and (d) personal meanings. It is thus valid to claim that there is no complete single therapy or treatment for chronic pain. Therefore, the current evidence suggests utilizing multidisciplinary individually tailored treatment including at least pharmacological treatment, physiotherapy, and cognitive-behavioural therapy to relieve the psychophysical symptoms, to maintain or restore physical activity, and altogether to improve the quality of life of a patient with chronic pain (Engel 1959, 1977; Crombez et al. 1999, 2012; Melzack 2001, 2004; Pincus 2004; Waddell 2004; Lame et al. 2005; Breivik et al. 2006; Gatchel et al. 2007; Gupta et al. 2007; Mackintosh et al. 2008; Flor 2012; IASP 2012; Nay & Fetherstonhaugh 2012; Roe et al. 2012).

In a systematic review by Scascighini et al. (2008) was concluded that compared with other non-disciplinary treatments, moderate evidence of higher effectiveness was shown for multidisciplinary interventions. In contrast to no treatment or standard medical treatment, strong evidence was found in favour of multidisciplinary treatments. No evidence was found that treatment variables, such as duration or programme components, were influential for the success of the intervention.

In a systematic review, Bondegaard et al. (2001) problematized the cost-effectiveness of multidisciplinary treatments because they found serious methodological problems in study designs and application of outcome measures. The quality of the cost measurements was characterized by an apparent lack of tradition using economic methodology.

As shown, there are cases when multidisciplinary treatment improves the quality of life but as demonstrated in a study (n=439) by Heiskanen et al. (2012) for 46% of the patients the quality of life improved, for 23% it did not change, and for 31% of the patients the quality of life decreased, when using a

multidisciplinary treatment approach designed and carried out at a pain clinic of a university hospital.

## 5.1 Pharmacological treatment

Advances in research have contributed to more effective drugs for chronic pain. Some drugs that are used in another illnesses have been found to be effective in chronic pain, such as antidepressants for depression and drugs for epilepsy but even the most powerful drugs reduce pain by no more than 35% for half of the users, indicating that chronic pain can only rarely be eliminated by currently available medication (Dahl & Lundgren 2006; Kalso 2009; Turk & Winter 2010).

Medication is designed to be used only in the short-term, and despite the evidence, many patients persistently use medication without any long-term benefit. It has also been found that those who misuse or overdose medications are more distressed (Main et al. 2008). Generally, pain killers (analgesic drugs) are at best ineffective for long-term use, and at worst they are addictive and have serious side effects causing more pain (Dahl & Lundgren 2006). The most commonly used medication in chronic pain are NSAIDs (non-steroidal anti-inflammatory drugs), opioids, sedatives/tranquillizers/relaxants, and antidepressants.

According to Kalso (2009), the effect of NSAIDs is based on their biochemical properties to prevent prostaglandin synthesis, particularly cyclooxygenases, COX-2, in different tissues. NSAIDs are effective when they are properly used in inflammatory conditions and when used in a combination with opioids in conditions such as tissue damage, postoperative use, cancer pain, arthritis, and migraine. Typical NSAIDs are aspirin, ibuprofen, diclofenac, and indomethacin. NSAIDs are used more in Finland than in the rest of Scandinavia. Common adverse effects of NSAIDs include gastrointestinal irritation, haemorrhage, anaemia, and increased cardiovascular risks in specific patient populations.

A review by Roelofs et al. (2008) concluded that NSAIDs are the most frequently prescribed medications worldwide and are widely used for patients with low back pain. They are effective only for short-term symptomatic relief in patients with acute and chronic low back pain. Perhaps as a result of the widespread use, NSAIDs cause the highest number of reported serious complications among all medications (Evans & Horowicz-Mehler 2010).

Opioids, such as morphine, codeine, fentanyl, and heroine, are morphine related drugs whose analgesic effect is achieved by the opioid receptors' ability to bind and block the nociception in the spinal cord, midbrain, pons, and in the cortex. Conditions where opioids are used include acute traumas, postsurgical pain, inflammations, acute ischemic pain, and cancer pain (Kalso 2009). They cause dependence and development of tolerance, and their withdrawal effects, such as cognitive dysfunction, anxiety, nausea, insomnia, vomiting, and respiratory depression, are the reasons why they are prescribed only for a short-

time use in acute pain (Main et al. 2008). However, there is also opposite evidence indicating that in order to avoid addiction opioids are not recommended for acute pain but just for chronic non-malignant pain. As a result, serious side effects are rarely reported and in long-term use opioids are as safe as in short-term use. Prescribing opioids is a common practice in developed countries (Eisenberg 2010).

In a review by Noble et al. (2010) it was concluded that many patients discontinue opioids due to adverse effects or insufficient pain relief but for some who could continue opioid use provided significant pain relief. Questions which remained inconclusive were quality of life and physical functioning.

Muscle relaxants, i.e., orphenadrine, chlormezanone, cyclobenzaprine, and diazepam, can be divided into two main categories, antispasmodic and antispasticity medications. The antispasmodic agents are further sub-classified into benzodiazepines and non-benzodiazepines. Non-benzodiazepines include a variety of drugs that can act at the brain stem or spinal cord level. These include, e.g., carisoprodol, metaxalone, zopiclone, and orphenadrine. Although these drugs may relieve skeletal muscle pain, their effects are non-specific and not solely related to muscle relaxation (Richards et al. 2012).

Sedative drugs are typically prescribed for sleeping problems which are common in chronic pain. In addition, the sedative effect is designed to relieve anxiety and worry about increasing disability; therefore, these drugs do not alleviate the pain (Main et al. 2008). They are also recommended for short-time use due to being addictive (Turk & Winter 2010). In rheumatoid arthritis relaxants were not found to be effective in improving pain over 24 hours to two weeks, but were associated with significant adverse events, predominantly drowsiness and dizziness even in short-term use (Richards et al. 2012).

Antidepressants, officially called tricyclic antidepressants, are frequently prescribed for patients with chronic pain due to their effects on the selective reuptake inhibition of serotonin and norepinephrine, which decrease pain and improve sleep without detected depression (Turk & Winter 2010). Antidepressants have been postulated to modulate pain through the central and peripheral nervous system. The mechanisms involve noradrenaline and serotonin neurotransmission, actions on opioid, ion channel activations, and possible effects on inflammatory cytokines (Verdu et al. 2008). Typical antidepressants are trazodone, imipramine, amitriptyline, doxepin, and nortriptylin. Antidepressants have been found to be effective in different types of neuropathic pain (Kalso 2009). In addition, antidepressants are not sedative and addictive, and the analgesic effect is separate from antidepressant effect (Main et al. 2008). Nevertheless, typical antidepressants' adverse effects are, e.g., problems on men's sexual life, dizziness, insomnia, agitation, cognitive impairments, and disorientation (Andrews et al. 2012).

A review by Chan et al. (2009) concluded that antidepressants have proved to be effective in fibromyalgia, chronic low back pain, diabetic neuropathy, post herpetic neuralgia and chronic headache whereas Richards et al. (2011) in their review concluded that they were uncertain whether

antidepressants had any effect on pain or functional status because the quality of the evidence was very low. The same results were also found by Urquhart et al. (2008) who stated that there was no clear evidence that antidepressants are more effective than placebo in the management of patients with chronic low back pain.

In general, there is no evidence of the cumulative effects of the long-term medication use to the natural homeostasis and to the synthesis of endogenous opioids which are much more effective in pain reduction than synthetic products and have no side effects (Andrews et al. 2012). Therefore, alternative and additional interventions to pharmacological approaches to manage chronic pain are required.

## **5.2 Physiotherapy approaches in chronic pain**

Physiotherapy is one of the rehabilitation approaches in chronic pain whose basis is to support the active rehabilitation management of a patient with chronic pain by different strategies where a patient has responsibility for his/her own rehabilitation. In physiotherapy, the patient is considered to be an active participator and has a right to express his/her own wishes about the strategies of physiotherapy. Instead of criterion of normality, the foundation of physiotherapy is individual reality and the right to be human (Talvitie et al. 2006).

The traditional physiotherapy education focussed on teaching biomedical issues, practical skills, and techniques, which are at present recognized as being important but insufficient in an effective physiotherapy practice, particularly in the case of chronic pain. With increasing knowledge and evolving practice, the physiotherapy culture has come to be fully aware of the social, psychological, ethical, philosophical, and cultural issues underpinning the work. This means that illness, such as chronic pain, has also psychological, cultural, and social aspects. Adherence to physiotherapy may therefore depend on personal lifestyle, social and material resources, which can be interpreted as disabled persons no longer wanting to be cured or made normal because culture and ethnicity influence the way illness is perceived, experienced, and managed (French & Sim 2004).

The aim of physiotherapy with patients with chronic pain is to decrease the consequences, impairments, and effects of pain, to advance everyday life activities, and enhance maintenance of social relationships with family members and others. Therefore, a physiotherapist needs to have comprehensive understanding of pain, leading to a holistic approach with a patient with chronic pain (Koho 2006).

In a holistic approach, the therapist should have the ability to ask the right questions so as to be able to listen and interpret the patient's needs to tailor an individual therapeutic intervention (Reynolds 2006; Drench et al. 2012). In addition, physiotherapy as a profession has undergone major changes, from

doctors telling what physiotherapists should do, to being an autonomous profession with responsibility that patients are given an accurate diagnosis and prognoses and are well-informed about the benefits, harms, and risks of the intervention (Herbert et al. 2009). However, evidence-based practice should not be utilized over client-centred practice, because in that case the individualism in therapy is forgotten. It is always the best applicable treatment for the patient that should be chosen, not the most effective treatment for the injury or impairment (Pirainen 2006; Whalley Hammel 2006).

There are a number of physiotherapy approaches but according to the literature, the following approaches are presented for chronic pain.

### **5.2.1 Physiotherapy modalities**

Pohjolainen (2009) divides the traditional interventions to thermic treatments (heat, cold packs), mechanical treatments (massage, lymph therapy), traction, electro therapy (TENS, transcutaneous electrical nerve stimulation, IF, interferential nerve stimulation, micro wave nerve stimulation, and others, such as DIDY, didynamic nerve stimulation), and hydrotherapy stating that all of these lack evidence of effectiveness in the case of chronic pain. In health care, all therapeutic interventions, including physiotherapy, need to be evidence-based. The therapeutic methods or strategies must be effective, indicating the scientific validity of a manoeuvre. Evidence-based physiotherapy can be defined as "high-quality clinical research, patients' preferences, and physiotherapists' practice knowledge" (Herbert et al. 2009).

Kroeling et al. (2013) in their review examined the effect of Pulsed Electromagnetic Field Therapy (PEMF), repetitive magnetic stimulation (rMS), and transcutaneous electrical nerve stimulation (TENS) on neck pain; PEMF and rMS were more effective than placebo, whereas TENS showed inconsistent results. They concluded that since the evidence was low they were uncertain about the estimated effect.

In a systematic review by Kumar et al. (2013) the effectiveness of massage was compared to placebo and relaxation in nonspecific low back pain. They concluded that the finding supported the effectiveness of massage therapy for the treatment of non-specific low back pain in the short term. However, there were common methodological flaws in the primary research recommendations arising from this evidence, which is why it should be interpreted with caution.

### **5.2.2 Exercise therapy**

Exercise therapy is regarded as a remarkable change in physiotherapy where the patient is considered as an active participator who learns new skills and restores impaired ones instead of being a passive recipient (Shephred & Carr 2005).

Exercise therapy is used in chronic pain against its adverse effects, such as restrictions in movements, dysfunctions or pain on moving, impairments, and consequently deconditioning due to passivity, immobility, and a decrease in

physical activity, seen with other deterioration in old age (Breivik et al. 2006; Butchart et al. 2009; Wilson & Palermo 2012). The vast majority of incidents are related to back pain (Waddell 2004) which probably also makes back pain the most frequently explored complaint.

Exercise therapy uses active and functional methods in order to restore and prevent the deterioration of the patient's functional abilities in daily living as well as also to decrease the restrictions in movements and participation to activities which can be manifested in a variety of forms. Therefore, exercise therapy involves also cognitive and individual capabilities of the patient (Pohjolainen 2009). Clinical experience has shown that patients respond favourably to an individualized exercise programme and feel that this type of programme involves them in their own recovery (Burleson Sullivan et al. 2012).

Typical approaches that are used in exercise therapy are aerobic exercise, anaerobic exercise, flexibility, and coordination. Aerobic exercise consists of physical exercise for long periods of time, such as distance running, walking, or playing soccer, with the training designed to increase the efficiency of the oxygen transport system. Conversely, anaerobic exercise consists of high-intensity work sustained for a short period of time, with the training designed to increase muscular strength. Stretching, ballet, and yoga are examples of flexibility, coordination, and relaxation (Shumway-Cook & Woollacott 2001).

In a review by Burleson Sullivan et al. (2012) the authors present conclusions of multiple results of therapeutic physiotherapy interventions. The authors concluded that aerobic exercise combats the deconditioning cycle and is therefore a key component in treating chronic pain because aerobic exercise induces analgesia. A decrease in pain perception was found that could last up to 30 min after the individual had exercised at an intensity of more than 75% maximal oxygen uptake for 30 min. The authors also state that yoga provides greater and potentially longer lasting improvements in patients with chronic low back pain than educational interventions alone. The goal of dynamic spinal stabilization exercises is to re-educate and strengthen the deep postural spinal muscles, such as the multifidi and transverse abdominis, thereby decreasing pain and centralizing symptoms. The authors concluded that there is limited research proving the efficacy of specific stabilization exercise and strengthening exercise for chronic pain.

Taken together, studies show that there is an agreement that exercise helps in the treatment of chronic pain, but it is still not clear exactly to which factors or which particular types of exercises the improvements may be attributed. At best, the literature suggests that the benefits of exercise are non-specific. Mior (2001) in his review came to the same conclusion, i.e., that in the case of chronic low back pain there is moderate evidence that exercise is effective in the short or long term, but there is conflicting evidence favouring one exercise over another and as to what is the effective mechanism.

In cases with intense pain active exercise therapy may not be the first option; instead, passive manoeuvres, such as mobilization or



manipulation may be implemented first to reduce the pain and gradually encouraging the patient to use actively the painful part of the body.

### 5.2.3 Manual therapy

Manual therapy is an umbrella term covering a wide range of philosophical approaches as a set of general beliefs, concepts, and attitudes. They have similarities in the examination process, variation in the role of applied anatomy and biomechanics, and the perspective of a particular model is often dictated by the origin of structures. The most prevalent manual therapy models are the Maitland concept, the Evjenth-Kaltenborn concept (The Nordic System), the McKenzie concept, and the Osteopathic concept (Cook 2007).

Manual therapy use primarily hands in treatment, which is why it is defined as “use of the hands in a curative and healing manner” (Lederman 2005). The effects of manual therapy are categorized into (a) biomechanical effects (range of motion gains), (b) muscular reflexogenic effects (relaxation), (c) neurophysiological effects (pain inhibition), and (d) psychological effects (satisfaction) (Cook 2007).

Most of the techniques used in manual therapy are passive in nature and are designed to increase the mobility of the restricted joint and surrounding tissues and normalize arthrokinematic gliding and rolling movement, and can be combined with exercise therapy. Immobilization, hydro-, thermo-, or electrotherapy or traction can be utilized when pain relief is desired. If an increased movement is detected, active exercise or stabilization exercises are used, or alternatively, splints, corsets, or taping. All manual therapy includes information, patient education, and home exercise (Kaltenborn 1993).

There are a number of studies of the efficacy of manual therapy alone or in combination with active exercise. Most of the studies have found manual therapy to be effective on pain with or without exercise, but there was no difference between the techniques. De Oliveira et al. (2013) had 148 patients with chronic non-specific low back pain in their study, and their aim was to analyse the immediate effects of a single, region-specific spinal manipulation versus a single non-region-specific spinal manipulation for the outcome measures of pain intensity and pressure pain threshold at the time of the assessment. According to the results, both groups improved in terms of immediate decrease of pain intensity but no differences between the groups were observed. The between-group difference for pain intensity and pressure pain threshold was 0.50 points (95% confidence interval = - 0.10 to 1.10) and - 1.78 points (95% confidence interval - 6.40 to 2.82), respectively. No adverse reactions were observed.

Simoneau et al. (2013) had 64 patients with mechanical neck pain. All of the patients were prescribed mobility exercises and received mobilization of their neck. About half of these patients also received manipulation of the upper back. After one week, patients who performed the exercises and received both mobilization of the neck and manipulation of the upper back noted greater relief of their neck pain. In the group that received both manual therapy

techniques, 75% had significant pain reduction and 70% experienced a noticeable improvement in their ability to perform daily activities. When patients only received neck mobilizations, only 19% found that their pain was reduced, and only 23% saw an improvement in their disability. The researchers concluded that the combination of exercise with neck mobilization and upper back manipulation was more effective in reducing pain in the first week of treatment.

Menke's (2013) meta-analysis included fifty-six studies from 1974 to 2010 which he classified into five classes (a) spinal manipulative, (b) exercise, (c) physiotherapy modalities, (d) usual medical care, and (e) control groups. He found that for chronic pain, 66% out of 98% was non-specific, but treatments influenced 32% of outcomes. Chronic pain treatments also fit within 95% confidence bands as predicted by natural history. Though the evidential support for treating chronic back pain as compared to sham groups was weak, chronic pain appeared to respond to spinal manipulative therapy. However, exercise with authoritative support is an effective strategy for acute and chronic low back pain.

Chronic pain has a multidimensional nature consisting of biological, physical, psychological, and social aspects. In multidisciplinary rehabilitation, each profession has its own special field, but they share the same holistic paradigm. Although physiotherapists are well educated and trained to a holistic approach, there are occasions when a physiotherapist's competence is not sufficient to manage a patient's psychosocial symptoms; that is when a patient with chronic pain needs a referral to specialist in that field.

### **5.3 Cognitive-behavioural therapy**

The relationship between pain and mental health has a long history, but it was not until the last century that mental health practice turned its attention to chronic pain. That is the reason why the current conceptualizations of chronic pain have vestiges of antiquity (Main et al. 2008).

Despite the progress made during the last decades in medical, technological, pharmacological, and surgical treatment of acute conditions and diseases, treatment of chronic conditions and chronic pain has seen less progress. Interventions that are used on acute conditions often fail on chronic conditions, causing disappointment as well as distrust in health care (Eimer & Freeman 1998). Therefore, confusion and vagueness exist in the rehabilitation of patients with chronic pain. Most of them have consulted with a number of health care providers (HCPs) with variety of diagnoses or none at all, and have undergone multiple failed treatments resulting in additional or increased psychological symptoms, such as depression, anxiety, post-traumatic stress disorder, phobias, somatizations, and anger or hostility (Winterowd et al. 2003).

The history of cognitive-behavioural therapy to pain management led to publication of a book by Turk et al. (1983), which incorporated practical



methods from a behavioural approach adding methods from cognitive therapy. Cognitive therapy procedure is a generic term comprising a wide range of approaches consisting of pain education and self-management to improve functioning. All of the methods cover the initial contact through assessment to reorienting the patient, building an appropriate relationship, and includes all phases of treatment along with maintenance.

The advantage of cognitive-behavioural therapy in chronic pain is that it has brought a clear focus to the contribution of thoughts and feelings to the experience of pain, helping the patient to change his/her behaviour. In addition, it helps the patient to apply skills to reduce the experience of pain so as to diminish the ways in which it affects aspects of functioning. The approach defines the experience of pain as a direct determinant of patient activity and emotional functioning (Eimer & Freeman 1998; Winterowd et al. 2003; McCracken 2005).

One recent modification of cognitive-behavioural therapy is acceptance-based treatment for chronic pain, i.e., Acceptance and Commitment Therapy, ACT, e.g., Dahl & Lundgren (2006) and Contextual Cognitive-Behavioural Therapy, CCBT (McCracken 2005), with a shift from struggling to control the pain, to letting the pain be and living life as desired, with the willingness to experience chronic pain. The pain behaviour is not seen as a product but a normal behavioural process of the patient's history, circumstances, and context, which influences behavioural patterns as verbal, physical, social, and emotional events. Other acceptance-based methods are the mindfulness, the relaxation method, and the values-based action method (McCracken 2005).

Acceptance-based therapies involves the Chronic Pain Acceptance Questionnaire, CPAQ, which can be used in many ways in therapy, e.g., for anamnestic purposes, for tailoring treatment, and for follow-ups. The questionnaire has been translated into many languages, including into Finnish by Ojala et al. (2013).

Multiple studies of different acceptance-based cognitive-behavioural approaches for chronic pain are found in the literature. Acceptance-based therapies have been proved to be successful in chronic pain treatment, but as found in a meta-analysis by Verhof et al. (2011) there is not one therapy that is superior to others. However, the evidence is that acceptance has been found to be associated with decreased pain, disability, and pain-related fear (McCracken & Eccleston 2003; LaChapelle et al. 2008; Baranoff et al. 2013), a reduction of depression, anxiety, and avoidance (McCracken et al. 2004), and a decrease of the frequency of medical consultations (Viane et al. 2003) as well as improved emotional, social and physical functioning and promoting a positive life attitude and commitment to everyday life (Viane et al. 2004) and higher work status (Kratz et al. 2007). Acceptance is also a very important component in changing pain behaviour (Volwes et al. 2007) and realizing that chronic pain may be a part of life (Clarke & Iphofen 2007). The statement that chronic pain is predominately a psychologically experienced illness can be approved from a psychotherapeutic perspective; if it was not, psychotherapy interventions

would be ineffective. However, evidence has shown to be reversed in chronic pain by psychotherapy while the evidence on the effects of medication and physiotherapy is conflicting.

## 5.4 Summary of models to understand pain

In the previous chapters different models and approaches of pain were presented. As shown, there is no consistency in the understanding of pain; instead, pain research is fragmented into several models associated with several research fields. Some disciplinary models to understand and explain chronic pain are presented in Figure 5.

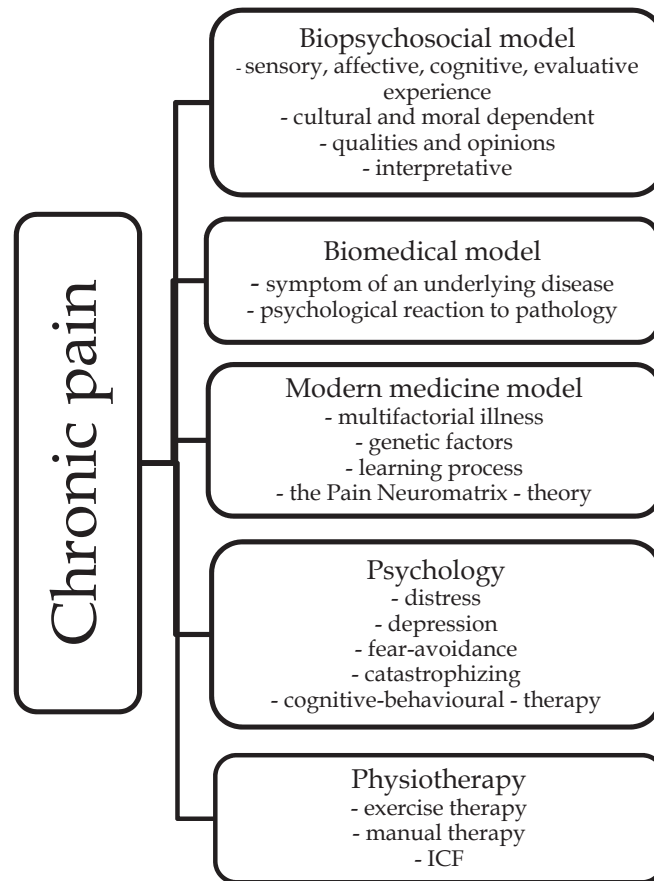


FIGURE 5 Some disciplinary models to explain chronic pain.

For the sake of a deeper understanding of chronic pain and in order to achieve a better clinical practice, maybe there should be a shift in the way we think about chronic pain, rather than to proceeding with more effective drugs and sophisticated therapy interventions. This is because despite all the advances they have supplied, chronic pain is still ahead of its management and has remained poorly understood. Concomitantly, the perspective needs to be turned from what has been explored in the research so far.

## 6 PHENOMENOLOGICAL APPROACH TO PAIN

Phenomenology is a descriptive philosophical tradition which has its roots in the work of Edmund Husserl (1859–1938). It is the science of relating things as they appear to us rather than things as they are. Therefore, phenomenological understanding would enable HCP to enhance their understanding of chronic pain, but at present, it is underutilized in training and practice (Carel 2011).

To date, there is no exact definition of phenomenology and there are many forms of it that are extensions of the work of Husserl and his teacher Franz Brentano (1838–1917), e.g., Jean Paul Sartre (1905–1980), Martin Heidegger (1889–1976), Maurice Merleau-Ponty (1908–1961), and particularly Wilhelm Dilthey's (1833–1911) philosophy in human sciences.

As a philosophy, there is an ongoing debate of whether phenomenology is a modern or postmodern paradigm (Finlay 2011). Phenomenological methods have been updated, among others, by Amedeo Giorgi, Herbert Spiegelberg, and Jonathan Smith. For historical reasons, its scientific foundations are most importantly based on philosophy, followed by cognitive sciences (Gallagher & Zahavi 2010). That is the reason why phenomenology is a qualitative method, but also a philosophy and a style of thinking (Merleau-Ponty 2009; Giorgi 2011a, b; Smith et al. 2011).

The main goal in phenomenology is to disclose structures that are intersubjectively accessible, the essence of the object; the intersubjective which is recognized only by personal experiences (Moustakas 1994) and generally discloses the personal being-in-the-world, i.e., existence (Merleau-Ponty 2009) and examines the relation to a personal everyday world, the "life world" (Sokolowski 2008; Laine 2010). van Manen (1990) states that in research, the way we experience the world is always questioned, and there is a desire to know the world where we live as human beings.

In the analysis, the aim is to describe human experiences and the meaning of the experience, and additionally, how persons bestow meanings to experiences (Laine 2010; Giorgi 2011a, b). Every experience is personal and in phenomenology, subjectivity is where it all begins. Thus, phenomenological

meaning analysis is always from a personal experience to a general description (Finlay 2011; Giorgi 2011a, b).

The “given”, perceptual object, such as pain, appears to consciousness by intentionality, which means that the mind is directed to something which is somehow important, the “given” has a meaning which varies according to contexts (Moustakas 1994). Meaning is created, not received, from a subjective horizon which has a nature of something for me, not something in itself (Vetlesen 2010). The perception of an object in consciousness is called “noema” and the act of perceiving how the object is perceived is called “noesis” (Moustakas 1994).

The perception is always somehow incomplete in regard to the object. This “perspectival incompleteness” appears as seeing only one side of the house at a time. Only one focus is in the centre and others are in the background (Gallagher & Zahavi 2010). Therefore the essence of the object, the noema, may be different from what is perceived but the essence can be reached on reflection. The essence of an object makes a thing what it is and without the essence it could not be what it is (van Manen 1990).

Perception of an object is not the truth, it is only the access to the truth which lies behind what is perceived and it is obtained with critical reflection, appearing in the consciousness (Merleau-Ponty 2009). This means that perceived objects do not appear in the mind as a picture of the outside world; the appearance may be different. Things not only exist, but they also have a meaning for their existence, and the way things appear is part of the being of the things (Sokolowski 2008).

## 6.1 The experience of chronic pain

Traditionally experience of pain is defined as *“emotional and psychological factors affect the way a person interprets or perceives neurochemically transmitted signals of noxious stimulation, and conversely, perceptions of the noxious stimuli determine that person’s emotional and psychological reactions to the physical sensations”* (Eimer & Freeman 1998).

Phenomenology is a holistic approach emphasizing the individuality of an experience which is perceived through and within the body in a particular space and time. Therefore, the first-person perspective of the experience is imperative in order to understand the experience in which body has a central role in the perception (Merleau-Ponty 2009; Perttula 2009). Finlay (2011) states that phenomenologists are interested in embodied lived experiences and the meaning of the experience because our body is a vehicle for experiencing, doing, being, and becoming. Thus, the body can be regarded as an embodied consciousness. The expression and dealing with the experience of pain varies between individuals, and moreover, within an individual. The experience of pain is context, mental, and emotional dependent, and pain is always true to the

experiencing person (Waddell 2004; Merleau-Ponty 2009). Thus, the only truth is a person's own statement of experiencing something (Saariaho 2012).

Moreover, dualism - keeping the mind and body apart - does not belong to phenomenology; instead, it belongs to understanding humans as one whole unity. There are no separate facets in the body; the body is both corporeal and mental, meaning that the person does not only have a body but he/she is the body (Merleau-Ponty 2009; Gallagher & Zahavi 2010). Moreover, the body and the mind interact, otherwise they have nothing in common and isolation of the mind from the body entails isolation of the mind from the world (Sokolowski 2008).

The visible body can be an object (a "thing") to others, but the other unseen subjective - the experiential body - is the "lived body" where the pain is experienced (Merleau-Ponty 2009). This can be explained by considering the body (a) as an object (that we possess) consisting of bones, nerves, cells, and liquids, and (b) as a subject (that we are), and together as the "lived body". The "lived body" is the body that experiences what is experienced, particularly in terms of pain, and also as the body that an individual recognizes as himself/herself. The objective body, which is typically used in medicine and physiotherapy interventions, is part of the "lived body" whereas the "lived body", which is silent in a non-painful state, can only be experienced. In pain, the unity is disrupted and the silent body becomes noisy when the painful part of the body becomes an object which the patient takes to a clinician to be fixed (Bullington 2009).

### 6.1.1 The experience

Experience is an ambiguous word which is defined by the Oxford dictionary as "*a practical contact with and observation of facts or events*" and "*feel an emotion or sensation*" (<http://www.oxforddictionaries.com/definition/english/experience>) or as philosophical meaning as follows: "*Experience is empirical knowledge which determines an object through perceptions; synthesis of perceptions*" (<http://www.philosophy-dictionary.org/experience>), indicating that the definition depends on the science and context.

van Manen (1990) states that an experience belongs to life and thus as a life event it can be called a "lived experience". Concerning this study, in addition to chronic pain being an experience it is also lived, which emphasizes its personal nature. A lived experience involves the immediate pre-reflective consciousness of life, which has temporal and qualitative patterns and an experience is the starting point and end point of phenomenological research.

According to Perttula (2009) the experience requires four basic components: (a) the one who experiences (subject), (b) the one which is experienced (object), (c) a relationship between them, and (d) a situation. By intentionality the subject recognizes the object to be somehow important or significant, which indicates the value of the object by meaning something to the subject. The object may be situated outside of the body, or, in the case of pain, it is inside of the body, which is the most common source of experiences. The

body is experiential and perceptive, following a paradox: the person experiencing is at the same time the experienter and the experienced (Merleau-Ponty 2009).

Broom (2007) states that experience is fundamental to being alive, and may be one of the fundamentals of being alive. In addition, experience involves the capacity to feel emotions, affection, and body states as well as being aware of thinking and stream of consciousness. Experience has a meaning, which is the reason why experience can be defined as a meaningful relationship between the experienter and the experienced in a certain situation (Perttula 2009). As a result, experience has something significant, cognitive, emotional, and contextual. Without them, experience does not have a meaning, and without a meaning, it is not an experience (Honkasalo 2000; Merleau-Ponty 2009).

In conclusion, an experience of pain is an embodied experience and the body is a source of experience (Broom 2007; Perttula 2009) as an ambiguous relationship between the person and his/her body (Buytendijk 1973). Therefore, when pain occurs, it is not only the pain that hurts but the body, e.g., an aching back (Scarry 1985) where the core problem may not be the pain self, but the individual responses to it, based on individual meanings (Dahl & Lundgren 2006; Giorgi 2011a, b; West et al. 2012a).

### 6.1.2 Giving meaning to an experience

An experience requires a meaning in order to be an experience, but the constitution of giving a meaning is a complex process. According to Broom (2007) meanings are constituted in layers since early childhood, so that in adulthood, every activated meaning is a tip of an iceberg of meanings, indicating learning from parents and culture. Sokolowski (2008) explains a meaning as a strange intermediate entity between the words - the way meaning is presented - and the object. Constitution is a combination of parts and wholes, presence and absence as modifications in the way things are being presented and more intricate ways of being manifested. Constitution is more complex in that pain does not have an object. Pain cannot be made concrete, making it inexplicable, which is manifested in that pain and its meaning are often expressed with the help of metaphors (Scarry 1985).

Giorgi (2011a) states that meaning answers the question "what is the experience like", i.e., a person's conception about an experience. Meaning is originated in the acts of consciousness consisting of a relationship between consciousness and object. Gendling (1997) describes giving meaning to an experience as a complex seven-phase interaction between the bodily intuitions and symbolizations as language and images. The seven phases are the following: (a) felt experience; a pre-verbal sensation of something, (b) recognition; recognizing what a word or symbol means at an embodied unconscious level, (c) explication; putting the felt sense into words, (d) metaphor; achieving new meanings, (e) comprehension; understanding is further languaged, (f) relevance; accumulation of meanings is put into context with other meanings, and (g) circumlocution; operates as previous meanings



are challenged and further meanings are created. Thus, meaning affects the identity and integrity of the person, is situational, and is influenced by past life, past experiences, and other persons' experiences and notions, which should not be ignored. The constitution of giving meaning to an experience of pain is presented in Figure 6.

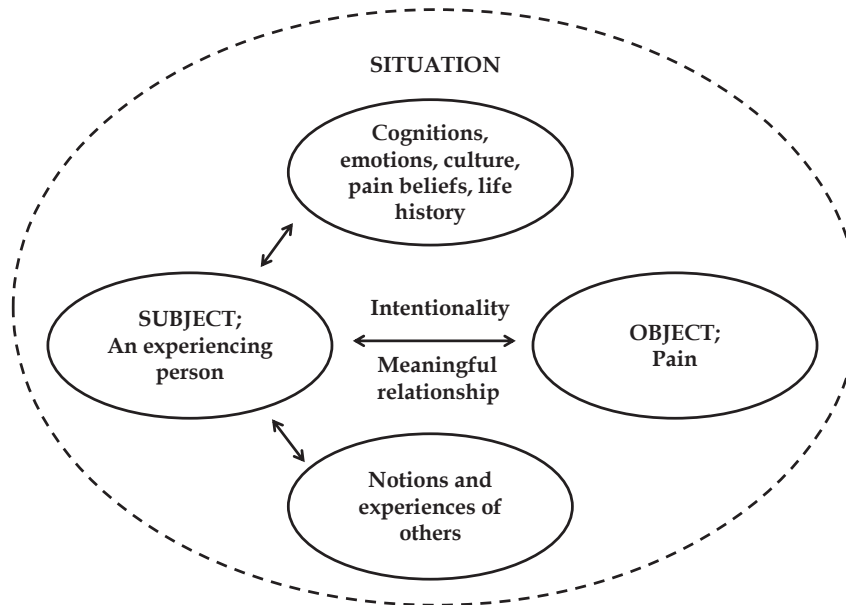


FIGURE 6 The constitution of giving meaning to an experience of pain by a person.

Meanings are not facts and they may not be valid, they can only be understood. It is noteworthy that there are irrationalities in all human understanding, because life may be partly irrational; it cannot be represented by a logical formula. In human sciences, understanding the other belongs to the science tradition (Dilthey 1986).

Everyone has his/her own "life world" which makes everyone's experience his/her own individual experience which cannot be known by others. They can only be understood by others. The access to the "life world" is private, which also makes the meaning of the experience private. Therefore, experiences of other persons can have similarities but they are not identical (Sokolowski 2008; Merleau-Ponty 2009).

In the understanding of the experience, the one who tries to understand needs to have either descriptive knowledge or acquaintance knowledge, where descriptive knowledge presents knowledge, e.g., from the media or from others, while acquaintance knowledge comes from personal experience (Russell 2008), making chronic pain difficult to understand to those without an experience of chronic pain.



## 6.2 A review of experience of pain studies

Pain is defined as an experience, but experience itself is very rarely defined in studies. In addition, the experience of pain is sparsely presented from an individual perspective; what does the pain mean to the person experiencing it? Moreover, pain is seldom examined directly or presented as a phenomenon. Instead, pain studies usually concern a body part (e.g., low back pain), an illness (e.g., cancer pain), an incident (e.g., postoperative pain), a structure (e.g., neuropathic pain), and restrictions or limitations in moving (e.g., questionnaires) are in line with medical tradition using diagnoses describing pain. As a result, a subjective experience has been generalized to, e.g., tissue damage, such as “sciatic syndrome” - a diagnosis which is in contradiction with the definition of a subjective experience. Finally, the treatment guidelines are designed according to diagnoses which neglect the suggested holistic approach to understanding the individual as a biopsychosocial unity.

The present knowledge aimed at understanding pain and treatment in clinical practice has resulted in poor outcomes (Breivik et al. 2006) indicating a call for more pain education and more individualized specificity for the management for chronic pain (Sessle 2012). Therefore, new insight of pain is required where individuality, experience, and personal meaning of the experience of pain are presented in order to have a more sufficient understanding of pain. Additionally, more alternatives and variation in application of treatments need to be implemented, which may be associated with, e.g., less distress and depression, increased physical and social activities, and consequently an improvement in quality of life. Pain education should not be limited only to HCPs; it should cover all pain patients and every man-on-the-street, with reforming and updating pain education starting in elementary school, because what is learned in childhood may contribute to interpretations and responses later in adulthood (Broom 2007). Thereby, it is rational to conclude also with regard to pain that unlearning as a child is perhaps easier than as an adult.

### 6.2.1 Chronic pain experience studies

One of the approaches to understand pain more comprehensively is phenomenology, which is not only a study method, a treatment guideline or a procedure in clinical practice, but a concept to understand chronic pain more deeply as a phenomenon, as an experience, and a personal perspective. However, at present, it is rarely used in pain research (Carel 2011).

In the literature, “experience of chronic pain” is often used, but only as a statement without any clarification or what it means in practice. A search (3/2014) in the databases PubMed, CINAHL, PEDro, and Cochrane with the following criteria: “Limits: Title word, Full text available, Years 2004–2014, Humans, English language, Adults”, provided 42 matches, but most of them were excluded because they consisted of, e.g., minority groups, children,

medication or alcohol use or psychopathology. After reading the whole texts, the following six studies dealing with the experience of chronic pain remained. The following presents the main summary of their conclusions.

Rustøen et al. (2005) explored the age and experience of chronic pain of people (n=4,000) who were mailed a pain questionnaire. The results showed that about 60% of the participants reported having a chronic pain, musculoskeletal problems being the most common. Participants in the older age group reported pain of longer duration and more comorbidities, but they had higher total quality of life scores. The younger age group reported the highest injury rates, and almost half of the respondents in this age group were not receiving any treatment for their chronic pain. In this study, experience of chronic pain was not defined and pain was measured by a quality of life questionnaire and VAS.

Fisher et al. (2007) explored the relationship between chronic pain and occupation with questionnaires and semi-structured interviews (n=13). As a conclusion, the authors state that the study illuminates the importance of therapeutic listening, the innovativeness of people who have chronic pain, and the possible therapeutic potential of occupation. The authors do not explicate experience, but wonder also that only a limited number of studies have delved into the experience of the person with chronic pain and suggest using auto ethnography or open-ended interviews to describe the experience of chronic pain.

In a study of Råheim & Håland (2006) the aim was to describe women's (n=12) lived experience of chronic pain and fibromyalgia. The women's stories point to a world experienced as fundamentally changed by a body in chronic pain, describing a struggle in which they feel that their existence is at stake. The authors quote Merleau-Ponty to define experience as follows: "lived experience refers to the way human beings give meaning to their situation".

Miles et al. (2006) interviewed 29 people on the experience of chronic pain. The results were that the people experienced different kinds of constraints imposed by pain, such as bodily constraint, activity constraint, and identity constraint. Despite the title suggesting that the purpose of the study was to describe the experience of chronic pain, it was not defined or clarified.

Hovind et al. (2012) examined how eight women experienced pain and pain treatment after breast cancer surgery using in-depth, semi-structured interviews. The results showed that the interviewees had expected pain in the acute postoperative period, but had not expected that the pain would persist. None of the women recalled having received information about pain. They took few analgesics and were generally sceptical about medication, mostly because of earlier reactions to drugs. Most of them were active and worked outside the home. Experience was not clarified.

Snelgrove et al. (2013) explored patients' (n=10) experiences of chronic low back pain by interviewing them. As a result, the authors state that the main challenge for participants was managing constant unchanging pain experiences and losses across all areas of their lives. Experience was not explicated but it

was described as “temporally distorted”, “viscous and long-lasting” or “entrapped in the present”.

The synthesis of the literature is that “experience of chronic pain” is used loosely and vaguely, and is often used as a synonym for words, such as “feeling, sensation” or “perception”, reflecting the traditional understanding of pain. Pain was also measured in some manner, either by a scale included in the study or by VAS, or both of them.

## 7 AIMS OF THE STUDY

There are a number of studies about the consequences and effects of chronic pain, but most of them are from a natural science perspective where the person experiencing pain is neglected. Phenomenology supports the holistic, multidimensional approach in human research which provides a deeper understanding of the personal "life world". Therefore, the purpose of this thesis was to search for a more profound understanding of the phenomenon of chronic pain from the perspective of persons with chronic pain and who have been treated for their chronic pain.

The specific research tasks were as follows:

1. How chronic pain is experienced?
2. What is the meaning of chronic pain?
3. What is essential in chronic pain?

## 8 THE REALIZATION OF THE EMPIRICAL PROCESS AS A WHOLE

Phenomenology sets aside theories, hypotheses, explanations, and causalities; however, phenomenology is not antiquantitative or opposed to theories (Wertz 2005). Its interests are what is experienced and how the experience is experienced in real life, with nothing added and nothing subtracted; in Husserl's words, "back to the things themselves". This requires phenomenological attitude, *epoché*- also known as bracketing - in which the former "natural attitude" is put aside to reflect the "given" with an unprejudiced attention (Giorgi 2011a), followed by the phenomenological reduction, which enables perceiving and describing the "given" in a fresh and open way (Moustakas 1994). According to Ashworth (1996), aspects that are put aside through the whole research process are: (a) scientific theories and explanations, (b) truth or falsity of claims being made by the participant, and (c) personal views and experiences of the researcher. Reduction is the most important access to finding the truth (Wertz 2005). As stated by Sokolowski (2008), phenomenology is the science that studies truth. In addition, phenomenology also examines the limitations of truth: errors, vagueness, and sedimentations.

Phenomenology, as a method, offers openness and rigor. Any topic that can be experienced is a good topic which must be described precisely as it presents itself (Giorgi 2011a, b). This means that the experience must be described as it was concretely lived, which includes freshness, richness and complexity (Finlay 2011). Concerning this study, there should be several meaning perspectives of pain, including, e.g., meanings of physical impairments, meanings of distress, divorce, culture and society, and meanings of alteration as a person.

Methods are scientific by virtue of being methodical, systematic, critical, general and intersubjective. Like in any other science, critical thinking, creativity, and reflective decision-making are required for variation and innovation (Giorgi 2011a). The phenomenological method is a method for studying experiences that are difficult to study with any other method. In this

study, phenomenology was also used in order to fill the gap between the theory of pain and the application of treatments.

Giorgi's method is a descriptive method following Husserl's tradition to describe the phenomenon as it presents itself to the participants. The method was initially developed and used in psychology, but as Giorgi has stated, it is applicable to any social science that works with human beings, e.g., qualitative health research. Despite the flexibility of the method which allows it to be modified and used in a range of fields, the researcher has to assume the attitude of the specific discipline and show sensitivity to detect the phenomena of interest (Giorgi 2011a, b).

Giorgi's four-phase method was chosen and applied to determine the essential meanings of chronic pain for the following reasons: (a) Giorgi's method has a descriptive tradition, (b) phenomenology is a science of experiences, (c) experience consists of meanings, and (d) the aim in phenomenology is to analyse the meanings of the experience and describe the structure of the experience and in analysis using an *epoché*, bracketing previous knowledge of pain aside (Giorgi 2011a, b).

## 8.1 Participants

The participants with different types of chronic pain comprised 34 patients with chronic pain who were recruited from four various sources in Northern Finland. Fifteen outpatients were from the Department of Physical and Rehabilitation Medicine, and six outpatients from the Pain Clinic at the same University Hospital. Four participants were obtained from the local back peer-support group and nine from the local pain peer-support group by the first author.

The participants in this study had: (a) chronic pain of at least three months duration as defined by the patient's own physician, (b) willingness to talk about the individual experience of chronic pain, (c) ability to read and write in Finnish, and (d) a minimum age of 18 years.

The ages of the participants varied from 26 to 73 years with a mean age of 48 years. Nineteen of the participants were women and twenty-one were married. Half of the participants were retired, and a fifth worked full-time. For 21 of the participants, the duration of pain was more than five years, and most of the participants had degenerative spinal pain. Most of the participants used a combination of medications. A detailed description of the participants is presented, e.g., in Original Publication I, Table 1.

Ethical approval for the study was obtained from the Northern Ostrobothnia Hospital District Ethics Committee. During the recruitment session, the nature of the study was explained by the first author or by a doctor and an informed consent was obtained from each participant.

## 8.2 Data collection

The first author (TO) collected the data by using open interviews in different locations (library café, coffee shop, participant's home, treatment room at the Department of Physical and Rehabilitation Medicine, or support group meeting room) from May to November 2011 after contacting each participant by telephone to ensure his/her willingness to participate. Each participant was allowed to decide the place of the interview where they believed they could speak freely and feel comfortable; thus, the interviews were performed in a conversational manner. A copy of the signed informed consent was also given to each participant. Field notes were not made during the interview.

The interviews were as open as possible, using open-ended questions (Smith et al. 2011) to allow the participants to tell as much as possible about the experience of chronic pain. The key statement was "Please, tell me about your chronic pain and how it started". Additional questions were used, depending on how much he/she revealed.

The recorded interviews lasted from 45 to 90 minutes and the interviews were transcribed by a professional transcriber. The complete collection of interviews consisted of 631 transcribed pages, ranging from 11 to 31 pages per participant. The transcriptions were not returned to the participants for comments.

## 8.3 Meaning analysis

The data were analysed using a phenomenological method according to Giorgi which is briefly presented in Figure 7.

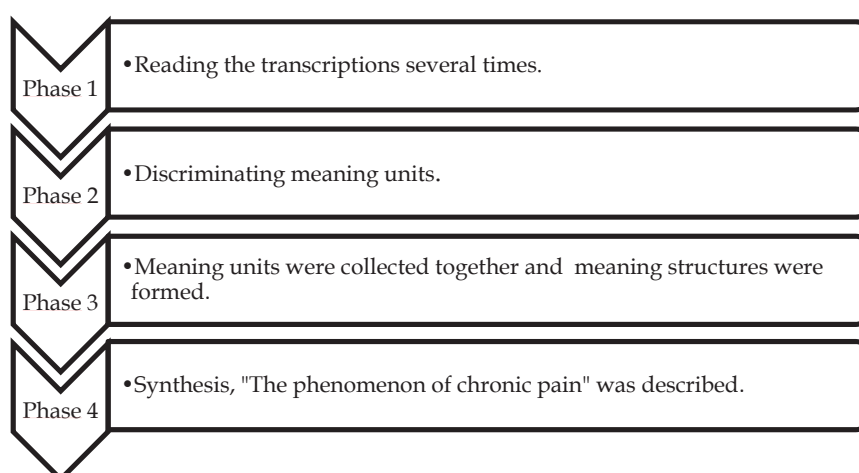


FIGURE 7 Giorgi's four-phase modified method (Giorgi 2011 a, b).

1. The first author read and listened to every interview simultaneously several times to get sense of the whole and bracketed his past knowledge of pain aside in order to encounter each participant's experience of chronic pain in a fresh manner (Giorgi 2011a, b; Smith et al. 2011).

2. In the second phase, the first author discriminated meaning units of chronic pain from each participant's transcription using his/her own words or expressions to find individual meanings of pain (Giorgi 2011a, b). Meaning units consisted of a few words up to a whole sentence and were noted every time a participant referred to pain.

3. Each participant's meaning units which he/she used to describe, for example, personal mood during pain, were collected, and meaning structures, as we named them, were formed. The meaning structures were arranged so that the most essential, from the participant's perspective, was placed on top, with the others placed below it and/or in parallel in an order that reflected how they were related to each other. The essence of each meaning structure was defined by how the participant described the experience of it, and how he/she referred it to other meaning structures. This organized collection of meaning structures constituted a subjective meaning network, which was the basis to write a meaning perspective, representing the entire experience of chronic pain of the participant. In this phase, the language was changed to reflect a third-person perspective (Giorgi 2011a, b).

4. In the synthesis, determining the essential themes of chronic pain - as the phenomenon of chronic pain - were extracted from the meaning structures of all 34 participants (Giorgi 2011a, b). Some meaning structures were combined and/or retitled to achieve precision and complexity following the phenomenological tradition.

In the meaning analysis, the experience of pain was described as it presented itself to the participants. The study had an adequate number of the participants as no new meaning units were found in the 34<sup>th</sup> participant's interview indicating a saturated data.



## 9 RESULTS; THE PHENOMENON OF CHRONIC PAIN

The results that emerged in the process - in the meaning analysis - comprised four phases which are presented in Figure 7. In the meaning analysis four essential overlapping themes of chronic pain were identified, namely: "Chronic pain affects the whole person" - which is the opening perspective for chronic pain - "Invisibility of chronic pain", "Negative meaning of chronic pain", and "Dominance of chronic pain" as the entities and thus, also presenting the qualities of chronic pain. Every essential theme constituted a different number of subthemes that were related to each other. The word "theme" was used only as a heading, i.e., indicating the meaning of pain.

The subthemes and their relations are presented in the Original Publications I-IV. The essential themes of chronic pain are presented in Figure 8. The results were a synthesis of the identified themes, which is presented next. The Roman numeral in the title refers to the published article.

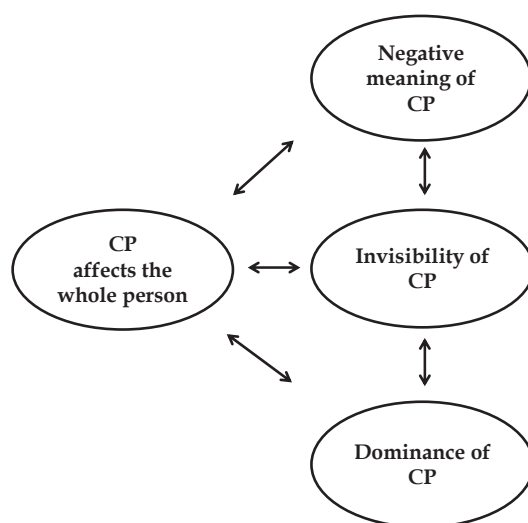


FIGURE 8 The essential themes of chronic pain and their relations. CP= Chronic pain.

## 9.1 A whole person is affected by pain (I-II)

In the analysis it was found that the themes “Chronic pain affects the whole person” and “Dominance of chronic pain” had a number of similarities, which was the reason for presenting them together.

The results of this study supported the insight that the experience of chronic pain affected the whole person. Physical and psychological pain could not be distinguished from each other; there was only a complete experience of pain. The key complaints were to a large extent related to psychological distress, sorrow, loneliness, and lost identity, which lowered their quality of life and thereby exacerbated psychological symptoms and increased the feeling of pain. The life before pain was past life, and the new life with a new identity needed to be reformed to redefine new normality with chronic pain. In addition to loss of identity, other losses, such as losing a job, losing a spouse, and losing the ability to move, i.e., to use the body to perform desired activities, inflicted additional psychosocial strain.

In the acute phase, pain affected only the physical body, but a persisting pain caused more harm, fear, distress, and other psychological symptoms which were more difficult to understand and cope with than the physical pain and physical impairments. However, the association with psychological symptoms and pain was agreed but remained elusive. For some, the distress was so severe that it led to alcohol and drug abuse, which caused other additional mental and physical problems as well as conflicts in relationships with others. Perhaps due to all these reasons, mental symptoms were also hard to bear and accept.

Chronic pain could be so powerful that it became master, dominating a participant's life to such an extent that he/she felt himself/herself as a servant. As master, pain did whatever it liked to do; pain was thus uncontrollable, indicating an optimistic idea that chronic pain could have been managed if it had been treated normally with medication.

The intensity of pain was not the only concern and grief, but the way in which pain gradually expanded to the thoughts demanding all attention, finally integrating the body and mind into an inseparable unity. Eventually, pain encompassed every aspect of life 24 hours a day, being the most important issue in life which could not be remitted. As a result, participants felt loneliness, helplessness, hopelessness, and desperation and considered that their life was not human life. For a final relief, some of the participants thought that suicide was one relevant option to liberate them from the misery. Therefore, it is misleading to talk about physical or psychological pain. Pain does not affect either one or the other, but the whole human being.

## 9.2 An invisible reality (III)

There have been attempts to make pain visible by brain imaging in order to understand and explain it better. However, despite the attempts pain has remained unseen, thus invisibility is one of the fundamentals of pain. Furthermore, because pain is unseen it cannot be measured, if it is understood according to the definition of pain as being an experience, which also makes the classification of pain questionable. The experience of pain was real to the participants, but according to the results, even today, the Cartesian tradition dominated the HCPs' attitude, education, and treatment, so that without physically detected evidence the existence of pain of the participants was not believed. The disbelief appeared as underrating or denial of symptoms or claiming that the pain was of imaginary origin, which caused additional distress, anxiety, depression, and separation from the family members. Disbelief was in contradiction with the official recommendations and guidelines and with the present scientific evidence of chronic pain that pain is an experience, not a sensation in which a physical source can rarely be identified as a cause for pain.

Because no pathology was detected chronic pain was not understood by HCPs, and the participants felt that nobody took responsibility of their treatment. The HCPs seemed busy and attempted to get rid of the patient as soon as possible. Nobody had time to listen and only the necessary treatment was provided, which was primarily symptomatic treatment, i.e., medication, which had many adverse effects, such as insomnia, memory deficits, dizziness, nausea, and vomiting.

The disbelief, due to invisibility of pain, was one of the major complaints to the HCPs, but it was the reality in which the participants had to live. Thus, patients with chronic pain have to live in a reality where some people may believe but only few can understand the effects and existence of pain.

## 9.3 A negative meaning of pain (IV)

The first step in revising the negative meaning of pain through reflection in order to manage pain is to make a distinction between the sensation and the experience of pain. The aversive sensation and the different consequences of pain are usually negative, but it does not mean that the meaning of the experience is also negative. Therefore, in chronic pain, pain itself may not be the core problem; instead, the problem may be the individual responses to it, based on individual meanings. Reflecting on the meaning of the experience is a beginning of an acceptance of chronic pain. According to the participants, defining pain only as negative, unwanted, and miserable did not make life

better; on the contrary, it could cause an increase of suffering and other associated symptoms, such as distress, depression, and loneliness.

The aim of reflection was to find some positive aspects in life instead of constant rumination on the misery of pain and a general negative attitude which made life more unbearable. Thus, negative thinking acted against itself in finding something positive in life. Reflection was to reflect on oneself, pain, values, and life from all possible perspectives and to scrutinize if pain was the only issue which made life miserable. The conclusion of reflection was that life could be miserable without pain and life could be enjoyed despite pain. The best values and the best supporters were found in the family and in support groups. Health care was usually in the opposition when it came to managing and furthermore, accepting pain, due to not being able to provide understanding, consolation, and belief particularly in cases, where no identified pathology was detected.

Acceptance of pain could alter participants so that they were able to enjoy life again. Accepting pain was concomitantly accepting oneself as a changed person, but not a worse one, despite deficits or impairments. Altered participants had a change in thinking so that pain was no longer an excuse for not doing something or avoiding doing what they liked to do. Desired activities could be done with modifications. The reflected new insight of pain meant the return of faith and hope back into life. The process of acceptance was long and uneasy and had multiple emotional and mental obstacles, but during the phases the participants grew as persons. This extended to all aspects of life, so they became more permitting and merciful persons. Without the initial reflection, life would perhaps have continued in an unsatisfying way, accompanied by a relentless chronic pain with a negative meaning.

In addition to that pain varied from day to day and it was associated with emotions, chronic pain was also context-dependent. Contexts where the participants were believed, accepted, and cared for were contexts where pain was experienced as alleviated and, naturally, also as reversed. The relationship to spouse and family members affected the experience of pain: the more satisfactory the relationship was the less pain was experienced. The more careful, loving, supporting, and the less critical or repellent the relationship was, the more obvious was the ability to manage with chronic pain. It was a question of being needed, believed, and accepted as a person in pain with impairments which deepened the relationship with close ones. Children were the highest priority for surviving and staying alive and the best motivation to manage with chronic pain.

## 9.4 The relation of the subthemes in the acceptance of chronic pain

The results of the study support the notion that in the management of chronic pain the focus should be more on psychosocial than pathological or physical complaints. This is presented in Figure 9. The results also confirm the poor effects of solely medical and physiotherapy oriented interventions. Instead, the results favour psychotherapeutic interventions, which do not mean that psychotherapy should be the only intervention, but rather that emotional, affective, and cognitive aspects of pain with pain education should be included in all kinds of interventions, and logically, also included in curricula, so that all HCPs have the ability to apply the widely supported holistic approach.

At present, chronic pain is regarded as permanent and thus, a complete recovery is unlikely, but not impossible. This makes the acceptance of chronic pain the most rational option, which is why all strategies and interventions that support acceptance should be applied while interventions that reject adjustment to chronic pain should be neglected.

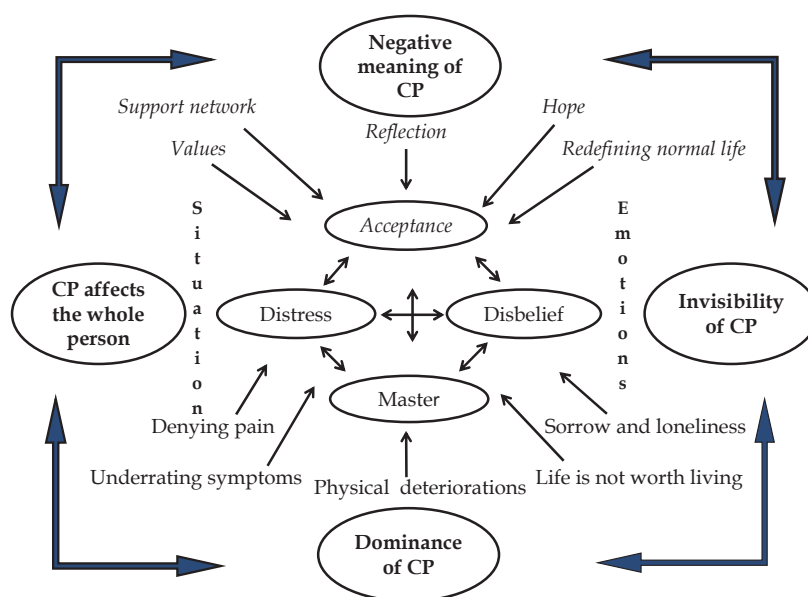


FIGURE 9 The most essential subthemes, which exacerbate (normal font) the experience of pain and reinforce acceptance (italics) of chronic pain. Chronic pain appears in a different manner depending on the perspective - affectivity, dominance, invisibility, negativity - it is examined. CP=Chronic pain.

As seen in Figure 9, all the three essential themes, "Chronic pain affects the whole person", "Dominance of chronic pain", and "Invisibility of chronic pain", with their most essential subthemes, "Distress", "Pain is the master", and

“Disbelief”, diminish the acceptance of chronic pain, and thereby managing chronic pain. On the contrary, they reinforce each other. Moreover, the subthemes “Denying pain”, “Underrating symptoms”, “Physical deteriorations”, “Sorrow and loneliness”, and “Life is not worth living” support the maintenance of the most essential subthemes, thus weakening the likelihood of acceptance and managing chronic pain. For example, in the event of divorce a patient with chronic pain may feel himself/herself abandoned, which worsens his/her self-esteem. As a result, he/she feels alone, which exacerbates his/her distress, which increases the effect of pain being a master, empowering the dominance of pain and thus, reinforcing the negative meaning of pain.

According to the results, the subthemes that reinforce “Acceptance of chronic pain” are “Reflection”, “Values”, “Support network”, “Hope”, and “Redefining normal life”. This finding supports the insight that psychosocial factors are in the midst in chronic pain. In addition, it also supports the notion of the ineffectiveness of medication and physiotherapy when solely applied. Finally, the results bring new insight that initially, the recovery from chronic pain needs to be initiated by the person himself/herself of his/her own personal desire based on his/her fundamentals of life. Adjustment to chronic pain may not occur without a personal awakening to the reality that chronic pain will persist, and the view that there could be a full life in the future despite chronic pain.

The acceptance of chronic pain seems to depend on the personal meaning of chronic pain which is usually negative due to its effects and consequences addressed as “Negative meaning of chronic pain”. If the meaning remains only negative it is unlikely that acceptance will occur, but the reverse may take place by an increase of distress, disbelief, and overpowering pain, resulting in an exacerbation of the experience of pain and a lowered quality of life. Revising the meaning of chronic pain is initiated through reflection in which the personal values of life are detected. According to the participants, chronic pain cannot be all negative if it is viewed from all possible directions and if it is understood as an experience.

A support network, such as family members, HCPs, and colleagues at peer support groups assisted in disclosing the meaning of pain by giving hope for a better life, and the revised meaning of pain resulted in an adjustment to living with chronic pain. They were also the best motivators by supplying reasons for life and points of view to look at chronic pain. Life with chronic pain differed from life before pain, but the participants commented that it was not a worse life; it had to be redefined. Living with chronic pain was normal life from now on, consisting of, e.g., limitations, restrictions, a variety of losses, rehabilitation, and rapidly changing emotions, which depended on the situation; in the same situation with different emotions the experience of pain was different; the experience of pain felt more agonising in association with a divorce than in connection with falling in love.

## 10 DISCUSSION

### 10.1 Method considerations

Qualitative studies can be evaluated by transparency, transferability, and reflexivity, which refer to systematic and continuous evaluation of the effect that the researcher has on the research process (Malterud 2001). In qualitative studies where psychological interest is the predominant focus, the intentional experiences reflect the perspective of individual subjectivity rather than a high-level truth or the objective state of affairs where the purpose is to discover the noematic correlate with its concrete context as constituted by individual subjectivity (Giorgi 2011a). In this study, the sampling process and collecting and analysing the data are described in details to keep the research process as transparent as possible and to provide possibilities to evaluate the authenticity and relevance of the findings.

The motivation for the decision to use the phenomenological method was to have a more profound understanding of pain by exploring the experience of pain from a perspective of persons with chronic pain. Additionally, the phenomenological method is the only method which discloses the meaning of the experience (Laine 2010; Giorgi 2011a, b) which, as demonstrated in this study, was decisive in the management of chronic pain. A descriptive phenomenological method is a valid method to find the meaning of the experience and it can be regarded as an extension of the spirit of science (Giorgi 2002; Perttula 2009).

Other methods which could have been used are content analysis and thematic analysis, but they lack the relations between the results and thus, the individual meanings of pain. In content analysis the results are categorised indicating separation (Krippendorff 2013), whereas in phenomenology the results overlap and are shareable among participants (Finlay 2011; Giorgi 2011 a, b). Thematic analysis requires themes that are enquired (Guest et al. 2012), which was not the case in this study having only one general question,



indicating individual interviews. Neither of the methods above unfolds the subjectivity and colourfulness of the experience of chronic pain.

There are many chronic pain questionnaires, but they concentrate on the consequences of pain and comprise a set of questions with few alternatives; as a result, the respondent may have to choose one which may not be the correct one for the person, just less wrong. Therefore, questionnaires do not reveal the individual perspective of the experience of pain which is the essence in pain exploration according to the definition of pain being an individual experience including complexity and richness.

The data used in this study were own and gathered for this purpose by the first author, and had a lot of variation, as suggested by Giorgi (2011a). The author collected the data by interviewing 34 patients with chronic pain experiencing different types of chronic pain, and the number of the participants was gradually increased until the data were saturated. The synthesis of the meaning analysis was carried out in a team led by an experienced author in phenomenological analysis. The research group discussed about the meaning units and meaning perspectives, and made the critical question according to the meaning analysis, which contributes to the trustworthiness of the results.

The results were underpinned by using an extensive body of current literature of chronic pain with sensitivity and as well as by the research method itself (Smith et al. 2011). In addition, due to the positive feedback from the participants the topic of the research was found to be relevant and important, which is an argument supporting the openness of the interviews and the fact that the participants found it easy to talk despite the unpleasantness of the topic. However, many of the participants were interviewed and listened to for the first time, which might have exaggerated the significance of some meaning units, in addition to which there might also have been memory biases on the part of the participants, but in the analysis the experience of chronic pain was described as it presented itself to the participants without any interpretations of the author (Giorgi 2011a, b; Smith et al. 2011).

In the meaning analysis, the author bracketed his previous knowledge of pain aside. As Giorgi (2011a, b) states, bracketing is a part of reduction, which means that "we should not let our past knowledge be engaged while we are determining the mode and content of the present experience". Merleau-Ponty (2009) has argued that reduction can never be complete, and that the past history and knowledge cannot be abolished. Giorgi (2011a, b) also explains that a present experience is always compared to a past experience and is often interpreted as being identical, which it is important to be aware of, but stating them to be completely identical leads to false conclusions.

Nonetheless, due to hermeneutics, in interviews there is always a possibility of interpretation by participants, so that they express their intentions in a way that is not exactly what they intended to express, as well as a possibility of interpretation in the data analysis. Nevertheless, although the results agree with other studies, being to a certain extent general, they should not be generalized to all patients with chronic pain or extrapolated to other



cultures due to the fact that, among other things, chronic pain is culturally dependent (Honkasalo 2000; Nay & Fetherstonhaugh 2012).

## **10.2 An overview of the main findings and their conclusions - a phenomenological approach to understanding chronic pain**

The purpose of this phenomenological thesis was to search for a more profound understanding of chronic pain with the specific research tasks: (a) How chronic pain is experienced? (b) What is the meaning of chronic pain? (c) What is essential in chronic pain?

The results indicate that pain was still not yet understood by HCPs and general population as an experience but as a symptom of an underlying disease. An experience of pain - a "lived experience" - is much wider and more complex than a sensation, consisting of cognitive, emotional, and situational factors as well, thus being essentially individual and learned (Sim & Waterfield 1997; Vlaeyen & Linton 2000; Linton 2005; Broom 2007; Flor 2012). In addition, in the analysis of the interviews it appeared that pain and health were different topics. Pain was just "pain", which did not affect health. A participant could have pain but still feel that he/she was a healthy person. Pain was described in many words, such as "it", "harm", and "burden", but only few described it as an "illness" or "sickness".

The starting point in the understanding of pain was to make a distinction between the sensation and the experience of pain. The sensation of pain is always negative or unpleasant; if it was not, it would not be pain at all (Jackson, 2000) whereas the experience of pain may be different. The meaning of an experience of pain which is composed in the reflection is not determined only by the sensation of pain but by all dimensions of pain. This leads to the conclusion that the only problem may not be the pain itself, but the individual responses that are based on individual meanings, i.e., the individual's conception about his/her pain (Dahl & Lundgren 2006; Perttula 2009; Laine 2010; Giorgi 2011a, b). Thus, applied in therapy, questions about the meaning of pain - the thoughts about pain - are more relevant and revealing than questions of what drugs a patient with chronic pain has been using or enquiring about the intensity of pain.

In clinical practice, this insight is not yet sufficiently considered, maybe due to the fact that traditional medicine still rules pain research and treatment (Jackson 2000; Gatchel et al. 2007; Steinhaug 2007), although the holistic approach is widely proved to be the general guideline. Therefore, pain education is needed in health care acknowledging that the key is that pain is an experience, but also at the elementary school level to emphasize that pain does not necessarily mean harm or damage or having to worry about which notion should be included in textbooks. Thus, despite the fact that pain is a moral, cultural, and social phenomenon (Honkasalo 2000; Nay & Fetherstonhaugh

2012) it is also pedagogical and educational issue which supports the multidisciplinary characteristics of pain.

In the analysis, three main outcomes of chronic pain emerged; (a) a whole person is affected by pain, (b) an invisible reality, and (c) a negative meaning of pain affected the participants' "life world". This should be interpreted as chronic pain filled their entire lives and the participants saw their life through pain. The life was pain and the pain was life, and pain defined the boundary conditions to life, which is in line with the studies by Morley (2008) and Drench et al. (2012). Pain was the first thought in the morning and the last in the evening. Life was organized by pain, according to its effects and consequences, and participants lived their lives on the conditions of pain. The participants felt themselves distressed, depressed, and hopeless under the dominance of pain when pain controlled their thoughts, making life itself painful, as was also found in the studies by Afrell et al. (2007) and Robinson et al. (2013). In the analysis, it seemed that the participants' lives repeated themselves with misery and despair without hope of remission, as a vicious circle without an exit. Chronic pain encapsulated psychosocial problems to others and to the participants themselves as lower self-esteem and quality of life because of disabilities, impairments, and loss of friends or a spouse.

In the analysis it was concluded that the most important issue in the management and acceptance of chronic pain was to believe in the participants' pain by their close ones and HCPs. Disbelief was based on lack of physical findings or other pathology - see also Thomas 2000; Lillrank 2003; Clarke & Iphofen 2005, 2008; Pesut & McDonald 2007 - which caused delays in treatment or not being treated at all, resulting in increased distress and other additional psychological symptoms that were more difficult to understand and manage than physical pain. The disbelief by HCPs and spouse was considered unfair and unexpected, because the HCPs were expected to be professionals in pain and to provide the best management for pain without speculation of its existence. Correspondingly, the spouse was expected to remain loyal in life's ups and downs and to be the first one to believe that the pain is real and the last one to deny it. As a consequence, disbelief caused the participants to question their own mental health and the existence of pain, speculating whether it was of imaginary origin after all, but still realising that it was real. Clarke (2007) came to the same conclusion: it is the patient's task to prove the existence of chronic pain and without detectable evidence even HCPs do not necessarily believe that the experience is true. The author also states that enquiring about the experience in a conversational manner is a foundation for a good therapeutic relationship, signalling understanding and caring, which fosters mutual trust and reliance.

Acceptance of chronic pain was basically accepting reality, as suggested by McCracken & Eccleston (2003), McCracken et al. (2004), McCracken (2005), and on the other hand, accepting oneself as an altered person with a new identity (Bullington 2009). Confessing the reality of a permanent pain which had to be lived with was one step closer to managing pain. Struggling against

pain was considered as a waste of time, resulting in an increase of disappointment, distress, and despair because pain always won, reminding of its uncontrollability. Therefore, it had to be left on its own and you had to get on with life with the realization that pain is an essential part of human existence (McCracken & Eccleston 2003; LaChapelle et al. 2008; Vetlesen 2010; Baranoff et al. 2013).

Unlike other studies, this thesis emphasizes a more profound understanding of chronic pain, namely that pain is an experience consisting of emotions, cognitive and behavioural aspects; it is also a situational, as well as cultural, social, moral, and pedagogical phenomenon (Honkasalo 2000; Melzack 2004; Broom 2007; Nay & Fetherstonhaugh 2012). In the recovery all these factors involving the individual meaning of the experience need to be explored. Furthermore, without pedagogical interventions at elementary and professional levels the change in the understanding of pain will not take place. Recommendations and guidelines may not be useful in clinical practice if these fundamentals of pain are not acknowledged and utilized by HCPs and general population. The essential themes and their relation to understanding chronic pain are presented in Figure 10.

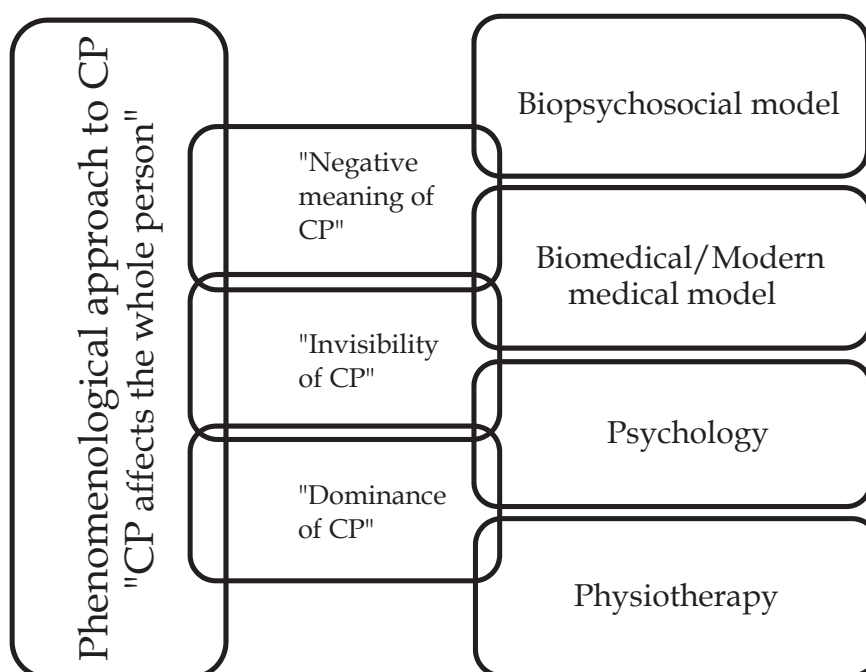


FIGURE 10 The phenomenological approach to understanding chronic pain. The figure presents the essential themes and their relations to research fields. The relation is partly theoretical. CP= Chronic pain.

### 10.3 Understanding the effects of chronic pain

Pain, particularly chronic pain, was not only a physical complaint; it was mostly an emotional and psychological construct where these factors accumulated and intensified the sensation of pain, leading to an exacerbated pain experience which respectively exacerbated the physical impairments and dysfunctions resulting in increased distress, despair, depression, worry, solitude, and a lowered self-esteem and quality of life. It has been found that patients with an intense chronic pain have an eight fold risk of depression compared to patients without chronic pain (Crane et al. 2013). Thus, it is valid to state that traditional physiotherapeutic interventions, such as electrotherapy, cold packs, and muscle stretching or strengthening to alleviate pain are inadequate and inappropriate, as is traditional medication (Roelofs et al. 2008; Urquhart et al. 2008; Pohjolainen 2009; Noble et al. 2010; Richards et al. 2011, 2012). It is a false belief that remission of the sensation of pain also remits the experience of pain. It is also a false belief to consider the body as a biological machine so that pain can simply be abolished by, e.g., removing pathology or restoring a joint function (Kolt 2004; Moseley 2008; Liebenson 2012).

The naturalistic view is to regard the body as an object, “a thing” which can be manipulated or operated in order to relieve pain. The “objective body”, the visible body, is only a part of the “subjective body”, “the lived body” in which the pain is experienced. The objective body is seen by others but “the lived body” is the body that makes a person what he/she is; it is the identity of a person. The person does not only have a body but he/she is the body (Osborn & Smith 2006; Merleau-Ponty 2009). Therefore, the body which can only be experienced cannot be fixed only by others.

#### 10.3.1 The new identity in chronic pain

According to the participants, the physical impairments and dysfunctions were easier to understand, accept, and manage than the psychological consequences. One of the reasons for this was that physical impairments were visible and they legitimized pain, whereas psychological effects were unseen for others and the person could have a stigma of being mentally unstable or ill for having something that did not really exist. The assumption that pain needed to have a cause or a physical, detectable source seemed to dominate in the understanding of pain, despite the present recognition that in chronic pain, a source can rarely be identified. However, even though many participants had physical impairments they attempted to hide them by moving in a certain way or by avoiding pain aggravating situations. The participants’ desire to be like others, to be normal, has similarities to a study by LaChapelle et al. (2008) and indicates a disrupted relationship with their aching body, as was concluded in a study by Bullington (2009).

Impairments were one of the losses due to chronic pain. Before the onset of pain the body allowed them to perform desired activities and, generally, to

move, but this was no longer self-evident. The body in pain was decayed and restricted, which narrowed life down and promoted withdrawal from others, leading to a more solitary life and a feeling of being left alone, increasing other psychological symptoms, such as distress, melancholy, fear, and hopelessness, which were also found in the studies by Thomas (2000) and Clarke & Iphofen (2008). It could also be concluded that those symptoms were time-dependent; the longer the duration of pain the more prominent and disabling the psychological symptoms were experienced compared to physical impairments. There were participants who were so hopeless and desperate due to the long duration of intense pain that they had attempted suicide. Suicide was considered as a final relief from pain and a therefore a rational decision is in accordance with a study by Tang & Crane (2006). The participants who had not seriously thought about suicide said that they had wished for a fatal accident to get rid of their constant pain. They felt that their life was not worth living with agonizing chronic pain.

In a study by Löfman et al. (2011) the data consisted of 2,310 suicides (1885 men and 425 women) committed in the province of Oulu in Northern Finland from 1988 to 2007. A total of 490 (21.3%) of the suicide victims had a history of hospital-treated musculoskeletal disorder, and the number of back pain victims was 133 (5.8%). The likelihood of suicide was 14.3 times higher for patients with hospital-treated musculoskeletal disorder than for the general population, indicating a high risk for suicide. However, according to the study, there is considerable variation in suicidality among patients with chronic pain, ranging from 9% to 68% in various samples.

All the effects and consequences of chronic pain had altered the participants as persons. Giving up the former identity was time-consuming and challenging because it was related to the identity of a handicapped person and a worse person. The participants judged themselves through others' eyes, how they thought they were seen by the others, not as they thought they really were. The formation of new identity was related to redefining new normality (LaChapelle et al. 2008), e.g., what activities they were capable of, considering retirement as an option, and four hours' sleep as sufficient. It was also found that participants who used to be active and physically capable had more obstacles than the less active participants in coping with the restrictions of the new identity. The new identity also affected the participants' roles in life, such as that of a father and spouse.

Blair (2010) explains normalcy as engaging in normally included activities that showed the participants either fighting against their pain or working through several emotions to maintain their previous personal identities and existences or building new ones but looking "normal". Ceding former identity, taking medication or undergoing surgery was described as "giving in", resembling very closely the results of the present study.

### **10.3.2 Cultural aspects of chronic pain**

Even though our culture has undergone changes during the last decades, the roles in the family have remained the same. From the results it can be concluded that men are still associated with manly activities and supporting the family; impairments may ruin these roles and cause a collapse to the manly identity. A woman's role in the family is still taking care of the children and performing housework. Inability to perform these tasks at home diminished women's femininity and role as a wife; this was interpreted as being an inadequate person who could not take responsibility as a mother and a wife. Furthermore, if the home was the context where the participants felt inadequacy, rejection, and disbelief pain was also perceived as more intense and disabling. This inspired some of the participants to move to another location or abroad, which also had an association with the relationship with the spouse.

Unfortunately, in some cases the partner regarded the participant as being too ill due to chronic pain and divorced him/her, which caused an increase in other problems, such as economic and parental problems, and a shrinking of social life. The results of the present study also showed that an unsatisfactory marriage can exacerbate the complexity of chronic pain leading to a worsened experience of pain, with psychological accumulation of symptoms resulting in lower quality of life. Respectively, a good and full marriage where a patient with chronic pain can feel accepted, believed, cared for, and needed may promote coping. Family provided the most badly needed emotional support and affirmation that a patient with chronic pain wants, namely; understanding, consolation, and hope for the better, which could not be provided by health care. This caused further disappointment and frustration with the public health service. Swift et al. (2014) concluded that participants viewed the involvement of significant others to be important because managing pain necessitates "being on the same page" and significant others also needed an opportunity to access support and information.

### **10.4 Pain remains unseen**

Despite the fact that pain is invisible the results of the study indicate that it can be made "visible" by believing the patient and taking seriously the patient's complaint of pain, which is a solid foundation for a satisfactory therapeutic relationship in order to manage chronic pain.

It is incongruous that 60 years after Bonica's recommendations of multidisciplinary treatment of chronic pain and 40 years after Engel's publication of the Biopsychosocial Model, the Cartesian legacy still dominates in the treatment of chronic pain, which is seen as a symptom of an underlying disease and not as an experience. This legacy supports dualism by separating the mind and body; as a result, participants were referred to specialists



according to their symptoms. In the present study this is manifested in that the participants were advised to contact a psychiatrist in the absence of physical evidence. If a pathology was identified it was treated as a biological disease by medication. The assumption was that the pain will remit if the pathology is cured, which is very often true with acute pain, but not with chronic pain, as explained before.

In this study the Cartesian legacy appeared as disbelief, underrating, and pain denial if an abnormality or pathology was not detected despite the fact that pain will remain unseen due to its nature. In extreme cases it was claimed that the participants imagined their pain and they were stigmatized as being mentally ill, which caused additional distress, worry, anxiety, and disappointment with the HCPs. The participants' impression was that they were left on their own, rejected from society, work, and social security to become second-class citizens who were not respected and taken seriously with their pain. The experience of chronic pain is always real, it can be appraised, and it is constant, which imaginary pain is not (Waddell 2004; Merleau-Ponty 2009; Saariaho 2012). Therefore, it is not a surprise that the participants began to suspect their own mental health because their pain was questioned by professionals who were supposed to represent expertise on pain.

The results of the present study show that it was not only HCPs who did not believe the participants' pain. This was also true of all the others who needed perceptual evidence for pain. A trauma, such as a broken bone, a ruptured disc or a torn muscle would have been sufficient evidence for pain. On the other hand, the participants often described the source of their pain with similar expressions. They attempted to make visible something that was invisible. Perhaps in that way it was easier for the participants to understand their pain as being of pathological origin and in fact, that was what they wanted from the HCPs.

Very often the participants wanted an explanation for their pain and requested MRI or other examinations. The explanation was not just for themselves but also for employers, friends, spouses, and social security. A postulate was that pain had a physical cause which could be identified by a device, and a detected pathology was given a name as a diagnosis which legitimized the existence of pain, and the participant was believed by others. However, as stated by Bullington et al. (2003) medical diagnoses are built around conceptualizations of the body as a physical, biomechanical machine where the relation between aetiology, organic source and symptoms is causal. Accordingly, pain has a diagnosis but the diagnosis is based on physiological or pathological findings, which may be absent in chronic pain.

In addition, a patient with chronic pain may have many diagnoses; there can thus be many sources for pain, although none of them alone may necessarily induce pain but in combination they may cause an experience of pain. Thus, diagnosis does not cure, neither does it explicate the source of pain per se, but at best, it may be a beginning to solve the complex coil as an "enlightened guess". This in turn may bring additional relief to a patient in that

he/she is taken seriously with his/her chronic pain. At worst, e.g., in physiotherapy, diagnosis may exacerbate the experience of pain as a result of focussing on minor pathology or pathologies which ignore or have nothing to do with the psychosocial dimension of pain as an experience of pain. Therefore, treatment planning should not be based solely on pathophysiology but on the aetiological and individual experiential factors as a whole, and their association with the pathophysiology, all of which are discussed in the dialogue during the therapy interventions - as a disclosure of the meaning of pain - not only in the interview.

#### **10.4.1 Chronic pain makes passive**

The participants revealed that emotions were associated with pain, either aggravating or alleviating each other, but for many of them describing their emotions with pain was not easy. They just mentioned their emotions with a word or two, such as "tired and bored" or "aggravates". Those who were able to talk about their emotions commented how they had become more irritated, less tolerant of loud noises or obstacles in life, being weepier, and not wanting any major changes in life: the more predictable the life was the more they preferred it.

That may have been one of the reasons why many of the participants described themselves as lazy or selective with tasks. They were not concerned about, e.g., unfinished chores, an untidy home or decoration of their home, but this alteration was not only their own decision but a result of the expectations and suggestions by others: a person cannot be in pain if he/she is active. An active, co-operative participant in pain was not believed.

There is still a strong belief that a person in pain should be passive, lying in bed, taking medication, and that pain will relieve with these strategies. On the other hand, in cases when a participant needed rest and relaxation he/she was blamed for being lazy or avoidant for not doing tasks only because he/she was a mean or weak person. The participants were told that their pain was only an excuse for not doing anything or to avoid doing unpleasant or undesired tasks. As a result of this, the participants' self-esteem was lowered and they felt that chronic pain had, in addition to other problems, also made them worse persons in the eyes of HCPs, work colleagues, but most of all their families.

#### **10.4.2 Pedagogical aspects in chronic pain**

Pain education or more broadly, pain pedagogy, should not be confined only to the HCPs; as was found in the analysis, the general population's knowledge of pain is primarily based on the tradition of biomedicine. The participants talked about their pain as a belief of organic or physiologic origin. Pain indicated harm, pain was a symptom of something, and that something must be found and fixed. The fixation would abolish pain, reflecting the traditional "cause and effect" - reasoning, as well as a belief in devices to identify and verify the existence of pain, e.g., by brain imaging (Wager et al. 2013). On the other hand,



this means that dialogue, the best method to identify and exchange knowledge and notions about pain, is forgotten.

Brain imaging has provided abundant help in the understanding of neural functioning and neural activity in the brain, but imaging does not explain the experience of pain or make pain visible (Davis 2011; Derbyshire 2011). This needs to be interpreted as follows: pain education is suggested to start in the elementary school, based on the current knowledge of pain as an experience and the fact that a person can have pain with or without physical trauma, pain involves different kind emotions, which we are permitted and allowed to express in the best appropriate way, and finally, the nature of pain is that it is unseen.

Those participants who had contacted a doctor at young age for their pain complained that they were not believed and that they did not receive any advice or information of their pain. If they had been educated at school or by a doctor their pain might not ever have become chronic. Disbelief and regular medication for pain were predisposing factors for chronification.

As explained before, the experience of pain is multifactorial consisting of physical, biological, emotional, and cognitive aspects which make it unseen, undetected, immeasurable, and unverifiable, even by technical devices. Thus, it can be stated with the present knowledge that pain is invisible and therefore if someone makes it visible it is not the experienced pain that is seen on the screen. Therefore, it can be concluded that the generally supported holistic approach to chronic pain was purely a rhetorical one; it is only used in recommendations and guidelines but not applied in clinical practice, as was also concluded in studies by Breivik et al. (2006) and Sessle (2012).

Furthermore, the pain education of HCPs seems to be poor: it has not been updated following the IASP's pain definition and treatment approaches. The poor knowledge of pain among HCPs was also found as underestimation of pain (Solomon et al. 2001), pain prejudices (Messerli et al. 2008), and using own attitudes as guidelines (Darlow et al. 2012), all of which do not give a professional impression of HCPs ability to treat chronic pain. An ambiguous conclusion was made in the study by Simmonds et al. (2012) where physiotherapists' knowledge of pain was found to be poor. A contradiction is that indication for treatment for most of the patients has pain and for 99% of back patients the primary complaint is pain (Waddell 2004; Koho 2006). It was shown that physiotherapists were not aware of the recommended guidelines and they used behavioural and biomedical approaches when treating patients with low back pain (Simmonds et al. 2012).

#### **10.4.3 The traditions as an obstacle**

However, the Cartesian conclusion for a poor treatment may not be so straightforward. The first contact with pain was usually to a health centre where expertise on management of chronic pain may have been lacking, partly due to short appointment time, which is usually no more than 20 minutes per patient. It is understandable that within such a short time a HCP cannot do

what he/she is able to do, but does what he/she can do, which was prescribing drugs or referring patients to therapy, e.g., physiotherapy, or in special cases a referring them to a university or central hospital, but such referrals were rare, perhaps due to guidelines restricting referrals between the organizations.

The poor pain education and poor awareness of the experience of pain maintained false pain beliefs and resulted in dissatisfaction with the effects of medication on the part of the participants. This might have been revised by pain education and informing the participants about the holistic interventions for chronic pain. Those who had received a holistic approach, as in the case of a multidisciplinary rehabilitation, gave positive feedback about the pain education, reporting that they had been listened to, taken seriously and believed, and that their psychosocial symptoms had been treated.

#### **10.4.4 The rigid structure of health care**

It could have been partly due to the poor design of the health care system which made the participants complain about inadequate examination, poor treatment plan, and understating attitude on the part of HCPs. In addition, current health centres do not have units specializing in pain or pain experts - they are found in university or central hospitals. Referrals to such units are not made until the pain has become chronic, which is unfortunately too late. At a chronic stage there is very little to be done by the pain experts and consequently the most effective and the most relevant way of managing chronic pain, i.e., prevention - to take a patient's experience of pain seriously and to believe the patient - is missed. This means that in addition to updating pain education, there is a need for reforming the system so that also the prevention of chronic pain is acknowledged by politicians, enabling HCPs to make decisions about their appointment schedule and concentrate on their profession, not on the documentation and paper work. Finally, due to the fact that pain experts are stationed in specific units it is suggested to enhance consultations with the aid of modern technology, such as virtual appointment with a pain specialist. This may also be a cheaper alternative than face-to-face appointment, which is certainly the best and preferable option.

Thus, the health care system needs to be more flexible and modern technology could be more often employed, particularly in cases where special treatment is not available nearby. At the moment, it seems that health care is more restricted by organizational procedures than HCPs' abilities and their willingness to accomplish their professional capabilities.

### **10.5 Managing chronic pain**

The results of the present study indicate that the management of chronic pain has two major issues. The first issue is to make a distinction between the sensation of pain and the experience of pain. The aversive sensation with the

unwanted consequences of pain is always unpleasant; together, these are interpreted as a negative meaning of pain. The negative meaning of pain is closely related to the negative pain beliefs, such as pain causes misery, pain is a punishment, pain leads to disability, and pain means low quality of life.

The aversion belongs to the nature of pain; if the pain sensation is not unpleasant it is not pain (Jackson 2000; IASP 2012). The experience of pain is wider, consisting of multiple factors, which may make the meaning of the experience necessarily not only negative; in short, experienced pain may have a meaning which needs to be disclosed by the patient in a dialogue with a HCP (van Manen 1990; Merleau-Ponty 2009; Perttula 2009; Laine 2010; Giorgi 2011a, b).

The second major issue is that the most effective help and the most encouraging support for coping with chronic pain can be received from the person affected and from the family. The other main source for help is the third voluntary sector, such as pain support groups. Health care is in opposition for not providing satisfactory holistic help for chronic pain, but only alleviation for the sensory dimension of pain, e.g., by prescribing a variety of drugs.

The participants claimed that in the recovery of chronic pain the first thing to do was to sit down and think about life, what is the meaning of life and what are the reasons to live. The beginning of coping with pain was realizing that pain was not the most important issue in life and that it was not only pain which made life miserable. The participants stated that the most important issues in life were family members; the spouse was the best emotional supporter and children the best reason to live. The participants also described very intensively how they enjoyed the normal, average things in life, such as morning sunrise, coffee on the balcony, and the caring relationship with a spouse. Life could be fine, full, and happy despite chronic pain, it was a question of values and attitude towards life. It could be concluded that by discovering the basic values life itself could be respected, despite chronic pain. Chronic pain was considered as an obstacle which could be overcome. It was not considered as a restriction for doing desired activities but as an excuse for not doing these activities. In phenomenological terms, the meaning of chronic pain became less negative, which encouraged further optimism to manage pain, away from constant pessimism and rumination. Therefore, one of the aims in therapy should be discovering factors which promote positive emotions, sense of success, and happiness into life.

### **10.5.1 Disclosing the meaning of pain**

It is notable that pain may not have only one meaning but many meanings, and they can be negative and positive at the same time, which is in line with one of the principles of phenomenology, being manifold in appearance (Sokolowski 2008). An example of many meanings is that the participants said that their relationship in marriage has become closer and they cared more for each other than before, and as a consequence, they had adjusted to living with chronic pain, but they would give anything to be released from the aversive sensation of pain.

In the results there were many similarities with studies by Sevenster (2007) and West et al. (2012a) where the experience of pain was an imperative source for meaning of pain; meaning is derived only from the experience. Chronic pain needed to be viewed from a broader perspective and life to be explored in more depth, including themselves as persons. A different vantage point enabled seeing positive changes in life, which would have remained unknown without a reflection. Despite the unpleasant sensation the participants felt themselves liberated from a vicious trap by empowerment and being accepted.

As reported by the participants, the restriction was more in their knowledge, negative pain beliefs, and attitudes than in their capabilities. Dysfunctions and impairments could not be removed and were hard to adjust to. Therefore, these had to be accepted and coped with. It was also a question of a strong desire to cope, to be an active participator instead of a passive receiver. In this case, an active participator should be understood in its wider meaning as revising the misbeliefs and maladaptive thoughts about pain, and general attitude towards life with pain, not only as an active participator in physical exercises. Without progress in these areas, despite the progress in physical activity, factual coping with chronic pain was unlikely to take place. One indicator of the progress was a shift in the meaning of pain from only negative into more neutral territory, from the restrictive without an exit to an obstacle which can be overcome, admitting the association of psychological symptoms with pain.

The individual meanings of pain, like the experience of pain, have qualities which depend on the severity of the experience; for example, despite equal intensity, there is a difference between the qualities of the meaning of cancer pain and labour pain. The more severe the experience is interpreted by the person, the more negative meaning is given to the pain, the more distress, anxiety, and fear, and as a result; the less coping beliefs are expected to occur. In addition, the meaning bestowed to chronic pain determines what will be done about it. Accordingly, as stated by Linton (2005), the thinking patterns set the stage for a behavioural response.

### **10.5.2 Accepting chronic pain**

The acceptance of pain required the acceptance of oneself as an altered person with a new identity, maybe a disabled but not a worse person. Acceptance of oneself depended on the acceptance of pain and vice versa. As the participants described the process they needed a lot of help from different sources. The most important help came from themselves and from the family through emotional support, affirmation, caring, believing, and understanding. The second best help was received from support groups where everyone was believed and accepted. The participants often praised the atmosphere, trust, and companionship in the support groups. Many of the participants would not be alive if they had not attended such groups. The team spirit was shared and everyone's voice was heard without dismissing anyone's opinions; as they put it, that only another patient with chronic pain can understand a patient with

chronic pain, which can be expressed in phenomenological terms as being-in-the-world in pain differs from without pain; expressed in everyday language, a shareable world unites patients with pain, and as stated above, also the opposite is true.

It can be concluded that chronic pain is more or less a psychological or mental phenomenon where the primary symptoms are disbelief, distress, depression, worry, fear, and loneliness, which is in line with the findings of, e.g., Sullivan (2001); Waddell (2004); Linton (2005); McCracken (2005); Morley (2008), and Saariaho (2012). Hence, the treatment must include support, education, caring, and co-operation instead of concentrating on drugs and physical rehabilitation. This does not mean that such approaches are ineffective and not useful, but relying primarily on those interventions reflects a lack of knowledge of all dimensions chronic pain, i.e., the profound meaning of chronic pain as an experience.

The participants of this study claimed that regular physiotherapy or medical interventions had only little positive effects on chronic pain, a notion that is supported in the literature, e.g., Richards et al. (2011, 2012) and Menke (2013). Schroeder et al. (2013) in their latest review concluded that there are minimal short- and long-term treatment differences in pain, disability, patient-rated treatment improvement, treatment satisfaction, health status, or functional improvement when comparing manipulation or mobilization therapy to physical therapy or exercise in patients with neck pain. These can be explained by saying that the individual perspective for life and incidents in life needed to be disclosed before any recovery from chronic pain might be expected. A negative attitude towards life was related to rumination on misery, which did not help the recovery. The recovery did not come from others but first of all from the person himself/herself. With a determined desire to survive and emotional support and affirmation acceptance of chronic pain is likely to take place.

Acceptance of pain resulted in an altered person who was able to enjoy life and the same things in the same way as before pain. The previously black-and-white thinking participants, who were restricted mostly due to their own attitudes and beliefs, had become more tolerant persons in all aspects of life. For the participants chronic pain was feature that was a part of life that could be managed, and certainly, not something worth dying for. Pain was only "pain" which did not directly affect health, but it was a reality which had to be lived with. Without the initial reflection about values of life and motivation for a change, the participants' life might have continued in a desperate, hopeless, and disabling manner.

Acceptance of pain is a multifactorial process and it is beyond the scope of this study to discuss it. The literature presents multiple benefits of the method which covers a variety of approaches (Reneman et al. 2010; Verhof et al. 2011; Baranoff et al. 2013). However, in a study by Blair (2010) a distinction was made between acceptance and adjustment to chronic pain. Adaption is a rational process, which involves choosing priorities and finding a way to make

important things happen. In acceptance, patients with chronic pain learn to graciously cede the small battles over pain, but in the end win the war of control as they change the way they respond to the situation. This is the final liberation from the dominance of chronic pain.

### **10.5.3 Chronic pain as a family pain**

The results of the present study show that chronic pain was not only a participant's pain but concerned the whole family. Although the participants consistently claimed that pain was suffered alone, meaning that pain could not be shared, the effects and consequences of it could be shared with others. To have people who listen, to have a caring family and faithful friends and some HCPs who take the existence of pain seriously were the fundamentals of management. This can be interpreted so that the genuine presence of another person is required, which is confirmed by how the participants described their loneliness, supporting the notions of Thomas (2000), Clarke & Iphofen (2008), and West et al. (2012b). Therefore, to be effective pain education should include all the family members where all the misconceptions, misunderstandings, false beliefs, and negative attitudes about pain are corrected, signalling to the patient that he/she is not left alone.

It does not help the coping of a patient at all if the other members of the family do not understand that chronic pain is much more than symptom of an organic pathology. Thus, the biggest misunderstanding of pain was in the need of a physical cause; pain must have an anatomic origin which can be found in a proper examination, e.g., with MRI, which indicates the dominance of biomedicine, seeing the body as a malfunctioning machine which can be fixed by replacing a part and using devices to locate the broken or malfunctioning part (Broom 2007; Bullington 2009).

### **10.5.4 An alternative to the present mode**

As addressed, the alteration of thinking concerns all persons who are involved in chronic pain. This requires more flexibility from the health care system to allow the HCPs to tailor the rehabilitation programme according to the individual needs of patients and enable inclusion of the whole family into the therapy, which is also suggested by West et al. (2012b). In addition, this insight means moving away from doctor-oriented - and more broadly, from medicine-centred therapeutic interventions - to other fields of research because as stated before, pain is not only a medical phenomenon.

This insight means that a doctor may not be the first option for treatment; instead, as recommended, a multidisciplinary team, consisting of a pain-specialized physiotherapist, a psychologist, and a doctor specialized in physical and rehabilitation medicine should form the core of the treatment team, collaborating with an educator, (how to best educate that patient), a social worker, (how to best help the patient on economic and work-related issues), and an anesthesiologist (how to best help in medication).



Furthermore, according to the results the only person who can understand a patient with chronic pain is another patient. Therefore, the team should include another patient with chronic pain as a mentor who is an expert in supporting with the effects and consequences of chronic pain and describing to the other members what it is like to live with chronic pain. The team and the patient may together design an individual rehabilitation programme for the patient. In this procedure, a patient with chronic pain makes an appointment with the team, instead of a doctor, which is cost-effective for all parties and saves documentation and thus misunderstandings between the team members. It also promotes co-operation of all members and patient-centred team work.

Despite the lack of clear evidence of the cost-effectiveness of multidisciplinary approach (Bondegaard et al. 2001) there is evidence that it is more effective than other approaches (Scascighini et al. 2008), supporting its primacy in the treatment of chronic pain. Therefore, qualitative indicators should be taken more into account than quantitative ones, such as money, when it is a question of a person's life.

The unlearning of a tradition, a deviation from the current praxis may take a generation or two, because as history shows, multidisciplinary treatment and biopsychosocial approaches are still waiting to become a routine in rehabilitation, but the change has to start somewhere and at some time. The present system may be too hierarch and bureaucratic, because it is rooted in a tradition where the HCPs' capabilities cannot be utilized in full and HCPs feel insufficient as well as frustrated. Correspondingly, the patients feel themselves to be disbelieved, rejected, and difficult patients who only overload the HCPs with their pain which the HCPs have minimal resources to alleviate.

### **10.5.5 Society and chronic pain**

Society is often forgotten in the management of chronic pain, which shows the entrapment in the tradition of pain belonging only to the health care system, which is also in contradiction to the multidisciplinary approach. Society is supposed to be responsible for the well-being of its people and take care that all people have the possibility to fill their duties to the society. For instance, if someone cannot work fulltime because of chronic pain he/she would have a chance to do part-time work or modified work. In addition, the possibility to change professions by re-education should also be more readily provided.

Chronic pain is not a stigma meaning that a person cannot do anything. Everyone can do something, and society needs to be more flexible in providing different options. Therefore, long sick-leaves and retirement do not cure and they are not permanent solutions for chronic pain and there is no evidence that they improve quality of life. On the contrary, they may encourage using passive coping strategies and if they improve quality of life the problem is perhaps something else than pain, such as dissatisfaction with own profession, conflicts with colleagues, or poor management at work, as was found in this study. Furthermore, they may reinforce the notion that chronic pain is invincible and must be conquered, and if it is not conquered there is nothing that can be done.

The preferred option is to stop fighting, admitting to reality and living the desired life with chronic pain with the best possible options.

The fact that the participants wanted to attend peer-support groups and other voluntary organizations indicates that also patients with chronic pain want to be needed and important, not only as person, but for what they can do and for what they can to provide to society and to other people. None of the participants wanted to be “second-class citizens” excluded from society and the company of others. A person with chronic pain is like any other person with individual needs and capabilities, which should be taken into account and utilized for others instead of being abandoned to survive alone and considered “bottomless expenditure”.

## 10.6 Clinical applications

Due to that chronic pain is predominately a psychologically experienced illness associated with psychosocial complaints, such as disbelief, distress, depression, fear of pain, varying emotions, avoidance behaviour, and poor self-efficacy, an alternative indicator, e.g., CPAQ, Chronic Pain Acceptance Questionnaire, is suggested to be used in clinical practice. CPAQ is validated to different languages, including into Finnish (Ojala et al. 2013). It consists of 20 statements of fundamental psychological aspects for experienced chronic pain mentioned above. To use the questionnaire for therapeutic aims the reader is advised to refer to the given literature.

It is noteworthy that CPAQ is not “a questionnaire” that is filled in by the patient and browsed briefly by the therapist; it is gone through in conversation between the therapist and the patient. In conversation the dialogical abilities of the therapist forms the essence, enquiring about the argumentation of, e.g., pain beliefs, fears, coping strategies. Briefly expressed, the aim in the dialogue is to disclose the meaning of chronic pain by determining the personal thoughts about the patient’s pain. In fact, in chronic pain conditions the quality of the dialogue between the patient and the therapist may determine the outcome of the whole therapy instead of technical skills or manual manoeuvres (Reynolds 2006; Clarke 2007; West et al. 2012a). Thus, in the treatment of chronic pain, it is ultimately rather a question of facing a person in pain than of application of therapeutic manoeuvres, an insight which should be included in, e.g., physiotherapy curriculum as conversational courses of how to interview a patient.

## 10.7 Suggestions for future studies

The main topic in this thesis was phenomenology and as demonstrated, it provides a deeper understanding of pain. Conclusively, it can be stated that



phenomenology can be used in health care as a bridge between different research fields to understand and explain chronic pain in order to achieve better clinical practice. The poor effects of the current therapeutic interventions may be related to the poor understanding of chronic pain. Therefore, a more profound understanding of chronic pain leads to more effective approaches resulting in better therapy outcomes.

During this process two big questions raised. The first question is: In whose interest is it to retain the problem of chronic pain by relying on one model instead of utilizing an additional model which, as shown in this study, provides a deeper understanding of chronic pain but is rarely utilized in health care (Carel 2011)? Due to the fact that persons are different means that their experiences are also different; as a result their experiences of pain require different kinds of examinations, a variety of intervention, and a selection of models.

The second question is: What is the worth of scientific evidence? All scientific evidence and all health care professionals favour the holistic approach, but after 60 years of waiting, chronic pain treatment is still not where it is supposed to be. The fact is that only few patients with chronic pain have received adequate treatment and hardly any have undergone treatment managed by a pain specialist (Breivik et al. 2006), and the risk for suicide in chronic pain is significantly higher than in normal population (Löfman et al. 2011). What more is required to alert us to reality?

Despite all the benefits of drugs, one possible obstacle may be the economic power of the drug industry, in the form of medicalization which maintains the illusion of the curative effect of drugs, standing in the way of the utilization of holistic approaches (Dahl & Lundgren 2006; Turk & Winter 2010). The belief in the curative effect of drugs was also stated by Kalso (2009), who reported that Finnish people use medication - especially NSAIDs - in pain, but it should be noted that victims with musculoskeletal diseases often use nonviolent methods and analgesics when committing suicide. Thus, the use of analgesics as a potential suicide method should be kept in mind when treating patients with musculoskeletal system diseases (Löfman et al. 2011). There is also contradictory evidence whether antidepressants reduce or increase the risk of suicidal behaviour (Andrews et al. 2012).

However, it is understandable that every pain patient wants rapid pain abolition, but in chronic pain a quick fix sometimes even a slow one is unlikely. Nevertheless, acceptance and adaptation are likely to take place. They are predominately psychosocial processes where primary help comes from the person himself/herself and from the close ones. There is sufficient evidence for the holistic and multidisciplinary approaches but we need evidence for the argumentation of their poor utilization because the progress in therapeutic interventions is not proportional to the scientific evidence about chronic pain during the last decades.

## 11 CONCLUSIONS

The purpose of this thesis was to search for a more profound understanding of chronic pain. In the meaning analysis there emerged four essential overlapping themes - (a) invisibility, (b) negativity, (c) dominance, and (d) affectivity - as the entities of chronic pain, discussed as three main issues of the study. The essence of chronic pain is the unity of the essential themes and the essence varies depending on the individual perspective. Therefore, it can be stated that chronic pain is a multidimensional negative experience, i.e., manifold in appearance, constituting parts and wholes, some of which are present and some absent, representing a phenomenological principle. Thus, phenomenology provides a competent insight to the understanding of chronic pain which should be observed in pain research and therapy applications.

The first main issue is the invisibility of pain: pain remains unseen and cannot be visualized because it is the nature of pain. Experience of pain is something else - in fact much larger - than an image of the brain when a person is feeling pain. Thus, sensation of pain is only a part of the experience of pain. Therefore, there is no criterion by which the experience of pain can be denied by another person. Denial of pain is similar to denial of other experiences, which do not have their own criteria either. This led to the conclusion that in therapy, the essence is to believe the patient. Believing the patient by taking his/her experience of pain seriously is the best prevention of chronification and a fundament of a satisfactory therapeutic relationship, which is built upon a dialogue between the patient and the therapist.

The second main issue is disclosing the meaning of pain through dialogue. Sensation of pain is always unpleasant - indicating a negative meaning - which is the nature of pain. If it was not unpleasant it would not be pain. Disclosing the meaning of the experience of pain may be different, something that may not be all negative; instead, pain may have a meaning in life and it may not solely make life miserable. Thus, life can be unbearable without chronic pain and vice versa, remission of chronic pain does not make life wonderful. Life can be enjoyed with chronic pain if the meaning of pain has been reflected from all possible perspectives and the negative pain beliefs are revised.

The meaning of pain is always individual because each person has his/her own "life world" with personal values, ambitions, and realities. The meaning of pain is not detected by any device but only in confidential dialogue with a HCP, spouse, or with another patient with chronic pain, or with all of them. Disclosure of the meaning of the experience of pain may involve liberation from the agony of chronic pain, but the disclosure must be initiated from the person himself/herself.

In sum, as the third main issue, chronic pain is experienced as a multidimensional illness where persons with chronic pain need a multidisciplinary rehabilitation programme in order to improve their quality of life. In the programme the focus is on remitting the most impairing psychosocial symptoms, such as disbelief, distress, hopelessness, and loneliness.

Taken together, understanding the phenomenon of chronic pain and its effects calls for a multidisciplinary collaboration in research, as well as in the implementation of the findings of research to clinical practice. This thesis demonstrates that phenomenology provides relevant new insight to the present understanding of chronic pain by including subjectivity and suggesting disclosing the individual meanings of pain.

## YHTEENVETO (FINNISH SUMMARY)

Krooninen kipu on moniulotteinen sairaus, jossa tiivistyvät fyysisten vaivojen ohella erilaiset psykososiaaliset oireet. Psykkisillä riskitekijöillä on suurempi todennäköisyys kuin fyysisillä poikkeavuuksilla altistaa, laukaista ja ylläpitää kroonista kipua. Kipu ja psyyke kuuluvat tiivistä yhteen. Kipu on siis enemmän kuin epämiellyttävä tunne tai fyysinen vaiva; kipu on yksilöllinen kokemus.

Krooninen kipu on globaalisti hyvin yleinen ilmiö. Arvioidaan, että joka viidennellä ihmisellä on krooninen kipu ja väestön ikääntyessä erilaiset krooniset vaivat vain lisääntyvät. Kipu on siten osa elämää ja hyvin harva ihminen selviää elämästä ilman kipua. Akuutin kivun uskotaan suojelevan elämää. Sen sijaan kroonisen kivun tehtävää ei tiedetä, jonka takia sen olemassaoloa on vaikea ymmärtää. Tämän väitöskirjan tarkoituksena oli selvittää kroonisen kivun syvempää ymmärrystä sitä potevien ihmisten näkökulmasta.

Väitöskirjan aineisto koottiin haastattelemalla 34 kroonista kipua kokevaa henkilöä. Tutkimukseen osallistuneiden yksityiskohtainen esittely löytyy liitteestä Original Publication I, Table 1. Haastattelut litteroitiin ja litteroitua tekstiä kertyi 631 sivua. Haastatteluaineisto analysoitiin Giorgin nelivaiheisen fenomenologisen metodin mukaan.

Metodin ensimmäisessä vaiheessa tutustuttiin huolellisesti jokaisen haastateltavan kuvaukseen kroonisesta kivusta lukemalla litteroitu haastattelu ja kuuntelemalla se samanaikaisesti.

Metodin toisessa vaiheessa kuvauksesta etsittiin erilaisia kivun merkityksiä eli merkitysyksiköitä, joissa haastateltava viittasi kokemaansa kipuun.

Analyysin kolmannessa vaiheessa samansisältöisistä merkitysyksiköistä muodostettiin merkityskokonaisuudet. Jokaiselle merkityskokonaisuudelle annettiin sen sisältöä kuvaava nimi. Merkityskokonaisuudet järjestettiin sen mukaan, miten ne olivat suhteessa toisiinsa ja olennaisin sijoitettiin ylimmäksi avaten merkitysperspektiivin. Merkityskokonaisuuksista muodostui kunkin haastateltavan yksilöllinen merkitysverkosto. Figure 2, Original Publication I on tästä esimerkkinä.

Neljäs vaihe oli synteesi, jossa kaikkien haastateltavien merkityskokonaisuudet tuotiin yhteen kuvaamaan kroonisen kivun ilmiötä.

Tulosten mukaan krooninen kipu rajoitti ensisijaisesti liikkumista, josta oli tullut vaikeampaa ja vaati enemmän aikaa. Monet olivat joutuneet luopumaan itselleen mieluisasta liikuntaharrastuksesta, mutta he olivat vastaavasti löytäneet jotain uutta sen tilalle. Useat haastateltavista olivat joutuneet luopumaan myös työstä ja jotkut jopa puolisoista, koska puolison mielestä haastateltava oli liian sairas. Unen laatu oli monella heikko, joka näkyi väsymyksenä, keskittymisvaikeutena ja ärtymyksenä. Krooninen kipu heikensi suhteita lähimmäisiin esiintyen riitoina, alistamisena ja vähättelynä haastateltavaa kohtaan. Kodista oli tullut paikka, jossa henkinen pahoinvointi ja kipu koettiin voimakkaampina.

Krooninen kipu oli jatkuvasti läsnä haastateltavien arjessa esiintyen hätänä, kärsimyksenä, suruna ja yksinäisyytenä heikentäen elämänlaatua. Elämästä ei enää voinut nauttia. Joillakin tutkimukseen osallistuneista oli itsetuhoajatuk-

sia ja muutamien kohdalla myös -yrityksiä. Muutamat toivoivat kohtalokasta onnettomuutta, joka vapauttaisi jatkuvasta kivusta.

Haastateltavat kertoivat, että kivun voimakkuus oli verrannollinen tunteisiin. Kielteiset tunteet lisäsivät kiputuntemusta ja myönteiset vastaavasti vähensivät sitä. Haastateltavien mukaan kipu ei liittynyt terveyteen vaan ne olivat kaksi eri asiaa. He kertoivat olevansa terveitä, mutta heillä vain oli "kipu".

## **Kroonisessa kivussa on neljä ulottuvuutta**

Merkitysanalyysissä ilmeni, että kroonisessa kivussa on neljä ulottuvuutta: (a) krooninen kipu vaikuttaa koko ihmiseen, (b) se hallitsee, (c) on näkymätöntä ja (d) se on negatiivista eli kielteistä. Akuutti kipu voi olla paikallinen, mutta kivun kroonistuessa raja kivuliaan ja ei-kivuliaan kehon osan välillä hämärtyy. Kipu laajenee täyttämällä lopulta koko kehon ja mielen halliten ihmistä ja hänen elämää. Fyysinen ja psyykinen kipu sulautuvat yhdeksi ja samaksi kipukokemukseksi.

Kipu on aina yksilöllinen, mutta sen ohella krooninen kipu näyttäytyy eri tavalla riippuen mistä perspektiivistä - kokonaisvaltaisuus, hallitsevuus, näkymättömyys ja negatiivisuus - sitä tarkastelee. Kroonista kipua ei siten voi yleistää, joten sen hoitosuosituksiin ja luokitteluihin tulee suhtautua kriittisesti. Ne kertovat vain oireista, eikä siitä, miten henkilö yksilönä kokee kroonisen kivun.

Haastateltavien mukaan fyysisen poikkeavuuden löytyminen jollakin menetelmällä tai teknisellä apuvälineellä, olisi helpottanut ymmärtämään kroonista kipua. Oletukseen liittyi myös uskomus, että poikkeavuuden tai fyysisen vamman hoitaminen johtaa automaattisesti kroonisen kivun häviämiseen. Näkemys edustaa perinteistä ymmärrystä kivusta, jossa kipu ymmärretään oireena jostakin vammasta tai poikkeavuudesta, jolle annetaan nimi eli diagnoosi, joka määrittää hoidon. Diagnoosi ei kuitenkaan kerro kivusta, eikä kokemuksesta, koska kivulle ei ole omaa diagnoosia. Poikkeavuus ja kipu eivät ole sama asia, eikä niiden välille voida aina rakentaa suoraa yhteyttä.

Kipua on pyritty saamaan näkyväksi useilla eri tavoilla, esimerkiksi modernin teknologian keinoin kuvaamalla aivojen toimintaa. Ajatuksena on ollut, että nähtyä on helpompi ymmärtää. Kuvantaminen ei kuitenkaan selitä kivun kokemuksellista luonnetta vaan ainoastaan fyysisiä rakenteita, hermotoimintaa ja verenkiertoa. Lisäksi kuvantamiset tehdään pääsääntöisesti terveille, joiden aivotoiminta on erilaista kuin kroonista kipua potevilla.

Tutkimuksen haastateltavat kertoivat, että näkymättömyys aiheutti suurimmat ongelmat kokemuksen uskottavuudelle. Ilman näkyvää vammaa tai poikkeavuutta, haastateltavien mielestä heidän kipuaan eivät uskoneet terveydenhuollon ammattilaiset, työtoverit eivätkä lähiomaiset. Haastateltavien mielestä nämä epäilivät ja vähättelivät kipua ja uskoivat heidän vain kuvittelevan olevansa kipeitä. Näkymättömyyden takia terveydenhuolto ei kyennyt selittämään kroonisen kivun olemassaoloa, eikä sillä sen takia ollut riittäviä keinoja

sen tuloksekkaaseen hoitamiseen. Tämän seurauksena haastateltavat kokivat jääneensä terveydenhuoltojärjestelmän ja yhteiskunnan ulkopuolelle.

Epäuskon takia monet haastateltavat kertoivat, että he olivat itsekin alkaneet epäillä omaa mielenterveyttään ja omia tuntemuksiaan. Luotettavin lähde kipukokemukselle on kuitenkin kokijan oma kertomus. Toistaiseksi ei ole olemassa kriteerejä, joilla toisen kokemuksen voi kieltää. Näkymättömyys ei tee kivusta olematonta. Ajatuksetkaan eivät näy, mutta se ei tarkoita, että ihminen ei ajattelisi.

Neljäs kroonisen kivun ulottuvuus on sen kielteisyys. Kipu tuntuu aina epämiellyttävältä; jos se tuntuisi miellyttävältä, se ei olisi enää kipua. Kiputuntemus on kuitenkin eri asia kuin kipukokemus. Kiputuntemus eli sensorinen ulottuvuus on yksi osa kokemuksesta, johon kuuluvat sen ohella myös affektiivinen -, kognitiivinen -, ja evaluatiivinen ulottuvuus; toisin sanoen erilaiset tunteet, uskomukset ja asenteet, elämäntilanne ja ympäristö.

## Kroonisen kivun kanssa selviäminen

Kipukokemuksen merkitys on eri asia kuin kiputuntemuksen merkitys. Niiden erottelu sekä merkityksenanto tapahtuvat reflektiossa, jossa kipua tarkastellaan monesta näkökulmasta ja se saa uuden merkityksen. Toisin sanoen sen, mitä henkilö ajattelee kivusta ja minkä arvon krooninen kipu saa henkilön elämässä. Merkitys voi olla vain kielteinen tai kielteinen ja myönteinen yhtä aikaa. Myönteisellä tarkoitetaan neutraalia merkitystä, jossa kipu ymmärretään elämään kuuluvaksi samanlaiseksi sairaudeksi kuin muutkin krooniset sairaudet.

Yksilöllisen merkityksen esille saamisessa voi käyttää apuna *”Kyselyä kroonisen kivun hyöksymisestä, CPAQ:ta”*, joka on pätevä ja luotettava mittari kroonisen kivun hyväksymiseen. Mittaria voi käyttää myös esimerkiksi anamnestisten tietojen ja selviytymisstrategioiden hankkimiseen ja pitkissä terapioissa arvioimaan lähtö- ja päättötilannetta.

Merkitys määrittää sen, miten henkilö toimii kivun kanssa. Kielteinen ja vakava merkitys näkyy tyypillisesti lisääntyneenä itsetarkkailuna, ahdistuksena, pelkona kipua kohtaan, passiivisena elämäntapana ja välttämiskäyttäytymisenä. Kielteinen merkitys on yhteydessä kielteisiin uskomuksiin kivusta, kuten kipu on tuskaa ja kärsimystä, kipu on rangaistus jostakin, kipu on epätoivoa ja kipu johtaa toimintakyvyttömyyteen.

Haastateltavat kertoivat, että kroonisen kivun kanssa voi selvitä, mutta sen kanssa on opittava elämään ja jonka olemassaolo on hyväksyttävä. Hyväksyminen tulee ymmärtää myös sopeutumisenä krooniseen kipuun ilman hyväksymisen tietoista myöntämistä.

Tutkimuksessa mukana olleiden mukaan vastaan taisteleminen, parannuksen etsiminen ja kivun kieltäminen olivat rahan ja ajan tuhlausta. Sen sijaan elämästä tuli tehdä oman näköinen ja tehdä niitä asioita, mistä nautti. Elämässä tuli olla tavoitteita ja haaveita, joita kohti edetä. Haaveet voivat olla vain haaveita, mutta ilman niitä elämä on köyhää. Näin elämästä tuli yksinkertaisempaa

ja selvempää, johon sisältyi toivo paremmasta elämästä kroonisen kivun kanssa.

Elämä kroonisen kivun kanssa on erilaista kuin ennen kipua, mutta ei vähempiarvoisempaa. Eläkkeelle jääminen kroonisen kivun takia ei tee elämästä kehnompaa. Se voi olla myös uuden ja paremman elämän alku, esimerkiksi uudelleen koulutuksen kautta. Haastateltavien mukaan elämästä voi nauttia kroonisesta kivusta huolimatta. Krooninen kipu ei yksin tee elämästä sietämätöntä, eikä kivuttomuus takaa onnellista elämää.

Hyväksyessään nämä hyväksyi samalla itselleen uuden identiteetin, joka oli armollisempi, joustavampi ja sallivampi itseä, kanssaihmiä ja elämää kohtaan. Prosessi oli pitkä ja siihen tarvittiin ennen kaikkea lähimmäisten, ystävien ja vertaisryhmien apua. Hyväksymisprosessin läpikäyneet, kertoivat, että ilman sitä, heidän elämänsä olisi jatkunut yhtä epätydyttävänä kuin ennenkin.

Todellisuuden hyväksyminen tuli lähteä itsestä, pohtimalla mikä elämässä oli tärkeää ja minkä takia kannatti elää. Tämä tarkoitti miettimällä elämää arvojen kautta. Motivaatio muutokseen selvitä kroonisen kivun kanssa löytyi pääsääntöisesti lähimmäisistä. Lapset olivat arvokkainta elämässä ja ensisijainen syy jatkaa elämää. Läheinen ja luottamuksellinen suhde puolisoon edisti kroonisen kivun hyväksymistä ja tarjosi sitä, mitä kroonista kipua poteva eniten tarvitsi; aitoa läsnäoloa, kuuntelemista, myötäelämistä ja lohdutusta. Näitä ei terveydenhuolto aina kyennyt tarjoamaan.

## Kehitysehdotuksia

Suomi oli mukana laajassa eurooppalaisessa kipututkimuksessa, jossa osoitettiin, että tutkimuksessa mukana olleista kolmasosa ei saanut minkäänlaista hoitoa krooniseen kipuunsa ja 40 %:lla kivunhoito oli riittämätöntä. Ainoastaan 2 % tutkimukseen osallistuneista oli ollut kipuun erikoistuneen ammattilaisen hoidossa. Suomalaisen tutkimuksen mukaan kipupoliklinikat voivat parhaimmillaan helpottaa joka toisen kroonista kipua, mutta joka kolmannen kohdalla käy päinvastoin. Joka neljännellä tilanne pysyy samana. Moniammatillista kuntoutusta kroonisen kivun hoidossa on suositeltu viimeiset 60 vuotta, mutta käytännön tasolla sen toteutus on vielä harvinaista.

Vallitsevaa tilannetta kuvaa se, että kivun hoito ja hoitosuositukset laaditaan pääsääntöisesti lääketieteen näkökulmasta. Kipukäyttäytyminen on oppimisen tulos, mutta pedagogiikan osuus hoitosuosituksissa on vähäinen. Sama koskee tunteita, vaikka tunteet ja kipu kuuluvat erottamattomasti yhteen.

Tämän väitöskirjan haastateltavien kroonista kipua hoidettiin yleisen tavan mukaan ensisijaisesti lääkkeillä, vaikka niiden teho on useissa tutkimuksissa osoitettu riittämättömäksi. Fysioterapia vaatii aina muuta terveydenhuollon ammattiosaamista tuekseen. Lääkkeet ja fysioterapia eivät poista krooniseen kipuun liittyviä tunteita, uskomuksia ja asenteita, surua ja yksinäisyyttä. Myös fysioterapian tavoitteisiin tulee kuulua löytää tekijöitä, jotka lisäävät myönteisiä tunteita, hyvää oloa, onnistumisia ja siten mahdollisuuden nauttia elämästä.



Tuloksissa ilmeni, että kivun kokemuksellista luonnetta ei ymmärretä vielä, kuten se tulisi ymmärtää. Kivunhoidon pääasiallisena tavoitteena edelleen pidetään kiputuntemuksen vähentämistä, joka on riittämätön tapa hoitaa kroonista kipua ja mikäli tavoitteena on ehkäistä kivun kroonistuminen. Yleisenä johtopäätöksenä on siis se, että kokemuksen puutteellinen ymmärtäminen tarkoittaa puutteellista hoitoa.

Voidaankin ehdottaa, että terveydenhuoltojärjestelmän toimintatapoja ja hoitoon liittyvää hierarkkisuutta tulee tarkastella kriittisesti. Sekä sitä, tapahtuuko moniammatillisuus ja poikkitieteellisyys (lääketiede, hoitotiede, fysioterapia, psykologia, kasvatustiede, filosofia) tasapuolisesti tutkimuksessa, hoitosuosituksissa ja käytännön toiminnassa. Krooninen kipu tulee ymmärtää laajemmassa perspektiivissä kuin pelkkänä patofysiologiana. Ihminen on kokonaisuus, jossa keho, mieli ja ympäristö kuuluvat erottamattomasti yhteen.

Kivusta tiedottamista tulee laajentaa koskemaan myös tavallista kansaa, alkaen peruskoulun oppikirjoista, miten kipu esitetään. Mitä nuorempana ymmärtää kivun kokemuksellisen luonteen, sitä helpompaa on tulla toimeen sen kanssa.

Kaikille on etua siitä, että kroonisia sairauksia potevat pidetään mukana työelämässä yksilöllisten kykyjen mukaan. Tämä lisää omanarvontuntoa, tarpeellisuuden tunnetta ja tekee elämästä merkityksellisen. Tulee myös luoda erilaisia toimintamalleja, joilla yhteisöllisyyttä ja sosiaalisia kontakteja ylläpidetään yksinäisyyden ja eristäytyneisyyden ehkäisemiseksi. Näitä ovat esimerkiksi työkokeilut ja vapaaehtoistyö.

Krooninen kipu on moniulotteinen ja monimutkainen kokemus, jonka selittäminen ja ymmärtäminen edellyttävät eri tieteenalojen yhteistyötä. Krooninen kipu on yksilöllinen kokemus, mutta se koskettaa myös lähimmäisiä, joiden merkitys selviytymisessä on keskeinen. Kroonisen kivun hoidon tulee olla aidosti moniammatillista yhteistyötä, jossa kroonista kipua potevalla ja hänen läheisillään on aktiivinen osallistujan rooli. He ovat mukana suunnittelemassa ja toteuttamassa yksilöllistä kuntoutusohjelmaa. Täten perinteiset ”parantaja, parannettava” -roolit eivät sovi tähän ajattelumalliin, eikä asiakaslähtöisyyteen, sillä kokija itse on oman kipunsa paras asiantuntija. Toinen henkilö ei voi tietää, miltä kokijan kipu tuntuu. Hän voi vain yrittää ymmärtää sitä asettumalla kokijan asemaan.

Fenomenologia on yksi tapa ymmärtää kipukokemus, mutta sitä on tois-  
laiseksi käytetty hyvin vähän terveydenhuollossa. Tämä väitöskirja osoittaa, että fenomenologinen näkemys syventää kroonisen kivun ymmärrystä yksilöllisenä kokemuksena, jossa keskeistä on yksilöllisen merkityksen selvittäminen, joka määrittää kipukokemuksen luonnetta ja siten sen kanssa selviämistä.



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## ORIGINAL PUBLICATIONS

### I

#### CHRONIC PAIN AFFECTS THE WHOLE PERSON - A PHENOMENOLOGICAL STUDY

by

Ojala, T., Häkkinen, A., Karppinen, J., Sipilä, K., Suutama, T., Piirainen, A. 2015.

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## II

### THE DOMINANCE OF CHRONIC PAIN - A PHENOMENOLOGICAL STUDY

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#### **ALTHOUGH UNSEEN, CHRONIC PAIN IS REAL - A PHENOMENOLOGICAL STUDY**

by

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## IV

### REVISING THE NEGATIVE MEANING OF CHRONIC PAIN - A PHENOMENOLOGICAL STUDY

by

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