Activity related pain in patients with musculoskeletal disorders

An explorative study

Elin Damsgård

A dissertation for the degree of Philosophiae Doctor in Health Sciences

UNIVERSITY OF TROMSØ
Faculty of Health Sciences
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PREFACE

I was introduced to pain medicine and nursing at the Pain Clinic at The Aker University Hospital in 2001, where I was included in working with group therapy together with nurses Sissel Jarmund and Axel Bilitz. During this period I was surprised to learn how patients with similar conditions experienced pain very differently, and I was fascinated by how the patients managed pain in diverse and personal ways. This was a time of learning and developing skills, on which this research has later been grounded.

This thesis was carried out at the University of Tromsø, department of Nursing and Health Sciences and at the University Hospital of Tromsø, department of Physical Medicine and Rehabilitation. It was funded by the Health and Rehabilitation Organization and by Helse Nord through Senter for aldersforskning i Tromsø. Many persons have been involved in the planning and completion of this work, and I want to express my gratitude to all of them, and some in particular:

My supervisors Professor Dr. Med Cecilie Røe of Ullevål University Hospital, Dr. med Audny Anke of the University Hospital of Tromsø and Professor Torunn Hamran of the University of Tromsø. They have, both individually and together, provided exquisite mentorship and they have always been enthusiastic and supportive.

Dr. Anne Dewar of University of British Columbia (UBC), Canada, for receiving me at UBC in September 2005, and for her great engagement in, and contribution to, my work.

My other co-writers: PT, Phd student Gyrd Thrane of the University of Tromsø, Dr. Terese Fors of the University Hospital of Tromsø. They have both contributed substantially to this research, as well as they have been my “allied”.

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Dr. Anne Fyhn at the University of Tromsø for fruitful methodology discussions.

My family for always being there.

My husband, Bjørn Braathen, for scientific, semantic, technological, practical, emotional and moral support in these times of many activities and sometimes pain.

Tromsø 08.09.09
Elin Damsgård

Content

ACTIVITY RELATED PAIN IN PATIENTS WITH MUSCULOSKELETAL DISORDERS

An explorative study

Abstract

Increased pain and fear related to general activity and exercise may be a barrier to rehabilitation of patients with chronic muscular-skeletal disorders.

The aim of the present research was to investigate the occurrence of activity related pain, and to explore its association with fear, psychological distress, self efficacy and pain (duration and distribution). The second aim was to explore how these psychological aspects and activity related pain associates with individuals' readiness to adopt a self-management approach to pain, and how patients described and explained such pain experiences.

Data were collected by questionnaires and qualitative interviews with out-patients at a Physical Medicine clinic at the University Hospital of Northern Norway.
Results showed that pain related fear of movement/(re)injury was a unidimensional construct, which was statistically significantly associated with increased pain during activity, also among individuals with non-elevated levels of psychological distress. Participants with high levels of fear of movement/(re)injury and psychological distress and weak sense of (pain) self efficacy were more likely to report pain during activity. They were also less ready to take a self-management approach to pain. Activity related pain was described and explained as a complex experience with diverse meanings. Initial fear of pain was re-interpreted under the influence of time, learning and own experience. Participating in social life situations was an important incentive to stay active despite pain.

List of papers.

This thesis is based on the following papers, which will be referred to in the text by their respective numerals.

1.
Damsgård E, Fors T, Anke A, Røe C: The Tampa Scale of Kinesiophobia. A Rasch analysis of its properties in subjects with low back and more widespread pain. Journal of Rehabilitation Medicine 2007; (39): 672-678.

2.
Damsgård E, Thrane G, Fors T, Anke A, Røe C: Activity related pain in patients with musculoskeletal disorders. Disability & Rehabilitation, 2009, accepted for publication.

3.
Damsgård E, Dewar A, Røe C, Hamran T: Staying active despite pain. *Pain beliefs and experiences with activity related pain among patients with chronic musculoskeletal pain.*
Submitted for publication

4.
Fors T, Damsgård E, Røe C, Anke A: Readiness to adopt a self management approach to pain – are profiles of subscale scores on the Pain Stages of Pain Questionnaire useful?
Submitted for publication.

Acronyms

ASES Arthritis Self Efficacy Scale

CBT Cognitive Behavioural Therapy

FABQ Fear Avoidance Belief Questionnaire

HSCL Hopkins Symptom Check List

LBP Low Back Pain

NRS Numeric Rating Scale

TSK The Tampa Scale of Kinesiophobia

PSCOQ The pain Stages of Change Questionnaire

WSP Wide Spread Pain

1. INTRODUCTION

1.1 Background.

Pain related to physical activities - whether they are exercise, daily life or work activities - seem to be a problem for many people with chronic musculoskeletal pain. Certainly, these pain experiences are also well known to healthy persons, especially in situations demanding extra muscular effort. For some patients it is not only the extreme efforts which are painful, but also more modest activities of daily life are reported as painful. For people with chronic musculoskeletal disorders, staying active and keeping a social life is an important way to improvement. Activity-related pain puts yet another strain on everyday life. It may be a barrier to participating in everyday life activities and work, and a barrier to rehabilitation treatment including exercise.

In this thesis it is sought to explore activity related pain in patients with musculoskeletal disorders, how it associates with different factors, and how it is explained and described by patients.

1.2 Pain

1.2.1 Definitions and perspectives

Pain is an experience known to most people, and there are at least 3 definitions of pain which are relevant to the focus of this dissertation. The International Association for the study of pain defines pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (International Association for the Study of Pain 1986). Pain researcher D. Price extended the definition as he describes pain as “a bodily sensation with qualities like those reported during tissue-damaging stimulation, an experienced threat associated with this sensation and a feeling of unpleasantness or other negative emotions based on this experience (Price 1999). He thereby added an evaluative aspect to the definition and introduced perceived

threat as a part of the pain experience. Nurse pain researcher R. Mc Caffery presents yet another perspective in defining pain as “whatever the experiencing person say it is, existing whenever he or she say it does” (McCaffrey, Frock, & Garguilo 2003). All these definitions bring fruitful perspective to the understanding of the very complex experience of pain. A common feature of the definitions is that pain is a personal experience. While the IASP and Price’s definitions underscore the link to actual or perceived tissue damage, McCaffrey leaves it up to the experiencing person to make such a link if relevant. In her definition, pain may as well be an experience without actual, perceived or feared tissue-damage.

Research during the recent years has brought expanded understanding of the complexity of the pain experience.The pain is processed and modulated in the nervous system by ascending and descending pathways between the cerebral cortex, other parts of the brain and the spinal cord (Gatchel, Peng, Peters, Fuchs, & Turk 2007). Genetic predispositions also seem to be of significance (Gatchel, Peng, Peters, Fuchs, & Turk 2007;Nielsen et al. 2008). Recent brain scanning techniques have revealed new knowledge about the major role of the brain in modulating the pain experience (Apkarian et al. 2005;Apkarian, Baliki, & Geha 2008;Gatchel, Peng, Peters, Fuchs, & Turk 2007). Psychological factors like anticipation and expectation of pain, attention to pain, and emotional state are part of pain perception. For example negative emotions enhance pain-evoked activity in the limbic system (Apkarian, Bushnell, Treede, & Zubieta 2005). Pain is also perceived, interpreted and expressed in a context of socio-cultural factors like for example social expectancies and environmental stressors (Gatchel, Peng, Peters, Fuchs, & Turk 2007). Thus, pain can only be understood and interpreted in a contextual perspective and its expression will vary across cultures (Bates, Rankin-Hill, & Sanchez-Ayendez 1997). The bio-psycho-social model of pain recognizes the physiological and psychological interactions of pain as well as the contextual importance of its social and cultural aspects (Gatchel et al. 2007)

1.2.2 Chronic musculoskeletal pain.

Chronic musculoskeletal pain is defined by the IASP as “pain which has persisted beyond normal tissue healing time” taken to be 3 months (International Association for the Study of Pain 1986). However, it has been debated that this definition does not take into account the subjective experience of pain and disability and the sometimes intermittent nature of pain (Smith, Hopton, & Chambers 1999). Chronification of pain is believed to occur as a consequence of continuous or repeated painful stimulation, like inflammatory processes. This stimulation may result in central and peripheral sensitization of the nervous system, meaning that a minor stimuli leads to perceived pain (Price 2002). Sensitization is considered a significant part of the manifestation of chronic muscle pain disorders and perceived stress and fear of pain seem to be associated with the transition from acute to chronic musculoskeletal pain (Arendt-Nielsen & Graven-Nielsen 2008;Houle & Nash 2008;O'Sullivan 2005). Chronic muscular pain is not always caused by, or even connected with obvious tissue damage (Kramis, Roberts, & Gillette 1996). This may be one of the reasons why it is difficult for patients as well as for health care professionals to understand, cope with and treat chronic musculoskeletal pain. Sometimes there is no obvious “cause” to attack.

Treatment of chronic musculoskeletal pain consists of several modalities. Pharmaceutical treatment, ergonomic guidance and physiotherapy are common approaches. Exercise programs are acknowledged in rehabilitation, and treatment based on physical activity and return to work is now standard in the western countries (Breivik et al. 2006). European guidelines for management of low back pain were established in 2004, based on international research (Burton et al. 2006). According to these guidelines, cognitive behavioral therapy, supervised exercise therapy, educational interventions and multidisciplinary (bio-psycho-social) treatment can all be recommended for non-specific chronic low back pain (Burton, Balague, Cardon, Eriksen, Henrotin, Lahad, Leclerc, Muller, & van der Beek 2006). Later years have seen an increase in behavioral and psychological interventions (Keefe et al. 2004), and the significance of social and cultural factors has been acknowledged

(Gatchel, Peng, Peters, Fuchs, & Turk 2007). Among the cognitively oriented models, theories built on fear of pain and physical activity have shown predictive value for pain disability among patients with low back pain, and there is increasing research on the validity of these theories in patients with other pain problems (Leeuw et al. 2007).

1.3 Psychological aspects of chronic musculoskeletal pain.

Some of the psychological factors considered important in the pain experience should be specifically mentioned in relationship to this thesis.

1.3.1 Self efficacy

Self efficacy refers to a person's "conviction that one can successfully execute the behavior required to produce the outcome" (Bandura 1977). The sense of self efficacy varies between individuals. A strong sense of self efficacy implies the belief in own capacity to perform a functional task, to manage a situation or to cope with a problem. Efficacy expectations are not global, but vary with respect to the situational context as well as personal factors. For example, to believe oneself capable of running 1000 meters is more realistic in summertime, and when in good shape. Self efficacy for speaking in public depends on the issue and the audience. A person's self efficacy is also an important aspect regarding behavioral change. Persons who have doubts about their own capacity and ability are less prone to change behavior as a result of information about the (threatening) situation. On the other hand, those who continue (threatening) activities that are in fact relatively safe will gain experience which corrects their perception of the situation and reinforce their sense of efficacy (Bandura 1977).

Within pain research self efficacy has mainly been assessed for coping with pain and for functioning. When reviewing literature on self efficacy in patients with chronic musculoskeletal pain it may be confusing to decide whether the self efficacy concerned functional tasks or coping with pain. However, the literature mainly agrees that the lack of belief in one's own capacity to manage, cope and function

despite pain, is a significant predictor of disability and depression in individuals with chronic pain (Arnstein et al. 1999;Arnstein 2000;Reneman et al. 2008). Improvement in health status, pain and self efficacy has been achieved by cognitive/learning treatment (Lorig et al. 2008;Wells-Federman, Arnstein, & Caudill 2002).

1.3.2 Psychological distress

Patients with chronic musculoskeletal pain are known to present with elevated levels of psychological distress. These factors may play a role in the transition from acute to chronic pain (Grotle et al. 2004;Pincus et al. 2002). However, there are some different interpretations regarding what these constructs imply. Several measures have been developed to assess them in different population including patients with musculoskeletal pain (Pincus, Burton, Vogel, & Field 2002). Thus, what psychological distress means and how it is measured in individual studies depend to a certain extent on the instruments available. In rehabilitation research in Norway, the Hopkins Symptom Check List, 25 question version, has been widely used to determine distress and it is translated into Norwegian (Brox et al. 2005;Grotle, Vollestad, Veierod, & Brox 2004;Sandanger et al. 1998). The instrument reflects general anxiety, depressive mood /depression and somatization combined in the overall construct of distress (Elliott et al. 2006;Pincus, Burton, Vogel, & Field 2002). People with chronic pain problems seem to develop depression, and research also shows that patients with chronic back pain are more likely to report depression. Thus, pain and depression seem to form a mutually reinforcing relationship (Gatchel, Peng, Peters, Fuchs, & Turk 2007). It is also common that patients with persistent pain feel anxious and worried. This may be especially true when symptoms are unexplained and the future is unpredictable and may appear bleak (Gatchel, Peng, Peters, Fuchs, & Turk 2007). Worries about persistent pain, and the consequently loss of function and economical problems, increases the burden. The vigilance to (threatening) symptoms from the body increases, thus enhancing perceived pain (Gatchel, Peng, Peters, Fuchs, & Turk 2007;Keefe, Rumble, Scipio, Giordano, & Perri 2004).

The distress concept as used in this theses also comprises somatization. The concept of somatization is described as a process whereby psychological distress is expressed in bodily symptoms (Noyes, Jr., Holt, & Kathol 1995). These symptoms may be heartbeat, shortness of breath, dizziness, gastrointestinal symptoms and pain. Unexplained by findings in a physical examination, the symptoms offer a frustrating experience to patients as they may be interpreted as signs of (unknown) physical disease.

1.3.3 Anxiety and fear

Fear and anxiety are well known components of the human pain experiences, characterized by a perception of situations as potentially dangerous. Although fear and anxiety are strongly related constructs and the terms are often used interchangeably, some conceptual clarifications of the phenomenon may be useful.

Anxiety and fear may both be described as signals of potential danger. Three components are significant: One is the psycho-physiological activation as a response to danger, for example heartbeat, breathing difficulties, muscle tension and hyper-vigilance. Another is the subjective interpretation of the signal and perception of danger. The third is behavior to cope with or avoid the dangerous event or stimuli (Leeuw, Goossens, Linton, Crombez, Boersma, & Vlaeyen 2007;Malt, Retterstøl, & Dahl 2003). While anxiety is a general feeling of unpleasantness and tension where the identification of threat may be obscured, fear is related to specified events, tasks or situations which are well defined and considered dangerous by the person experiencing fear (Malt, Retterstøl, & Dahl 2003;Thambirajah 2005). Fear may be described as a universal primary emotion in human beings across different cultures (Thambirajah 2005). The fear experience may be inborn or learned, and develops through the interaction of innate and learned elements (Thambirajah 2005). The learning of fearful reactions to different situations and stimuli unfold in the context of environmental and cultural factors as well as personal experience and differences in vulnerability (Leeuw, Goossens, Linton, Crombez, Boersma, & Vlaeyen 2007). Hence, to a certain extent fear is contextual. *Phobic fear* is referred to as abnormal

fear, characterized by being difficult to explain rationally, out of proportion to the demands of the situation, beyond voluntary control and leading to avoidance (Malt, Retterstøl, & Dahl 2003).

1.4 Pain related fear and the fear avoidance model

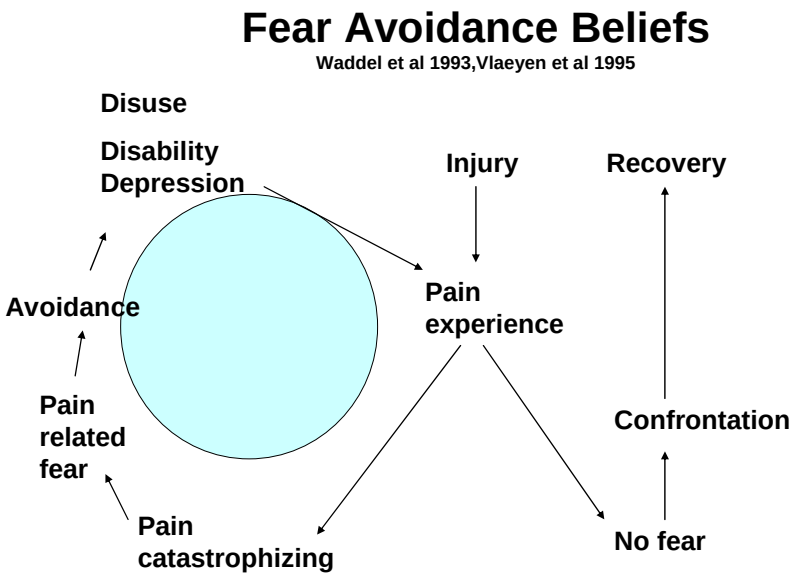
In clinical situations, the distinction between pain related fear and anxiety is blurred. The phenomenon may be defined as fear that emerges when stimuli that are related to pain are perceived as a main threat (Leeuw, Goossens, Linton, Crombez, Boersma, & Vlaeyen 2007). Acute pain serves as a warning signal, and the reaction to acute pain is desirable. The goal of removal from pain is "built into our body's neuromuscular circuitry; we reflexively withdraw from painful stimuli" (Leder D 1990, p 78). However, fear of pain, fear of work related activities, and fear of (re)injury have been described in patients suffering from chronic pain; a situation where there is no longer any obvious somatic cause for pain (Leeuw, Goossens, Linton, Crombez, Boersma, & Vlaeyen 2007). The fear then is concerned with a stimulus' potential to increase pain as well as pain being a signal about (potential) danger. As well, it is reasonable to view this kind of pain-related fear in a learning perspective (Boersma & Linton 2005). In this perspective fear is developed as a consequence of repeated experiences of unexpected painful activities. For example, a person might become anxious when physical activity remains painful beyond the expected healing time, or when pain increases while he or she expects it to decrease (Boersma & Linton 2005). One could speculate whether pain unexplained by injury and tissue damage brings on more fear than pain with a well documented cause.

One way of managing fear and anxiety is by avoiding the threatening stimulus. Thus, if physical activity provokes pain, it is avoided. However, if pain itself is threatening it is difficult to escape for chronic pain patients as pain is more or less constantly present. Both avoidance and hyper-vigilance reduce anxiety short term, but may be counterproductive in the long run (Leeuw, Goossens, Linton, Crombez, Boersma, & Vlaeyen 2007). Pain-related anxiety and fear are important predictors of mal-adaption to persistent pain. Fearful patients tend to focus on the pain, thus report

increased pain intensity (Arntz, Dressen, & Merckelbach 1991). As well, an individual's physical performance has shown associations with pain-related fear. Both clinical and experimental studies have shown associations between high levels of pain-related fear and disability and decreased ability to perform physical tasks (Keefe, Rumble, Scipio, Giordano, & Perri 2004).

The fear avoidance theory contributes to the research of how chronic pain and disability develops. The theory is based on the elements of fear and activity (Waddell et al. 1993). The essence of the theory is that an injury, or a pain experience, is interpreted differently in different people. If the person is catastrophizing about the pain, this will lead him or her into a stage of pain-related fear and consequent avoidance of physical or work activities (Vlaeyen et al. 1995). *Pain catastrophizing* implies anxious patients' tendency to expect extreme negative consequences and their own low ability to cope with pain when injured (Keefe, Rumble, Scipio, Giordano, & Perri 2004). Pain catastrophizing is strongly correlated to pain disability and intensified pain (Leeuw, Goossens, Linton, Crombez, Boersma, & Vlaeyen 2007) and is related to many negative outcomes such as depression, medication use and limitation in social life (Keefe, Rumble, Scipio, Giordano, & Perri 2004). The passive life-style and withdrawal from activities and work brings the person into a vicious circle of disability and depression and persistent pain (Fig 1).

Figur1. The fear avoidance model for how chronic muscular pain develops from an injury or pain episode to chronic pain.



The significance of this model in explaining the transition from acute to chronic pain has been investigated in several studies, with diverging results (Buer & Linton 2002;Vlaeyen & Linton 2000). However, growing support for the fear avoidance model is being established, theoretically and clinically (Leeuw, Goossens, Linton, Crombez, Boersma, & Vlaeyen 2007), and studies suggest “that pain-related anxiety and fear are important predictors of how patients adapt to persistent pain” (Keefe, Rumble, Scipio, Giordano, & Perri 2004). Until recently, the significance of high pain as a predicting factor has been a subject to discussion, but more recent research reveals the important role of high pain intensity in itself as a threatening experience (Leeuw, Goossens, Linton, Crombez, Boersma, & Vlaeyen 2007). The fear avoidance model was developed for patients with low back pain, and there are still questions about the relevance of this model in other patient groups (Leeuw, Goossens, Linton, Crombez, Boersma, & Vlaeyen 2007).There is also lack of knowledge concerning the concepts of fear avoidance and fear of movement/(re)injury. Avoiding physical activity may be rooted in more than the notion of pain as a sign of danger. There is reason to ask whether avoidance may

also be rational, well considered behavior, based on what patients have experienced or been informed about (Indahl 2004).

Fear of movement/(re)injury is one construct within a theory of fear avoidance (Kori SH, Miller RP, & Todd DD 1990;Vlaeyen, Kole-Snijders, Boeren, & van 1995) (Figure 1). It assumes that people interpret pain as a sign of potentially harmful bodily processes, and physical activity as a condition for this process. In an experimental study Arntz and colleagues (2004) showed how interpretation of pain as related to tissue-damage made subjects rate pain as more intense than without such an interpretation (Arntz & Claassens 2004). This supports the hypothesis that avoidance of activity is rooted in a misinterpretation of signals, as people connect the pain experience with tissue damage and probably potentially harmful processes. One of the instruments developed to assess pain-related fear is the Tampa Scale of Kinesiophobia, which aims at assessing pain related fear of movement/(re)injury in patients with chronic muscular pain (Kori SH & Miller RP 1991;Vlaeyen, Kole-Snijders, Boeren, & van 1995).

Treatment of pain-related fear by cognitive therapy and exposure in vivo are promising in patients with higher levels of pain related fear (Keefe, Rumble, Scipio, Giordano, & Perri 2004). In patients without such fear treatment aimed on decreasing fear may be counterproductive (Boersma & Linton 2005).

The Pain Stages of Change Questionnaire, based upon a trans-theoretical model of how people change also comprises questions which mirror fearful perceptions of pain (Kerns et al. 1997;Kerns et al. 2005;Prochaska, DiClemente, & Norcross 1992). The questionnaire is intended to assess readiness to adopt a self management approach to pain, and measures both the extent to which an individual accepts personal responsibility for pain control as well as the extent to which the individual is considering making behavioural changes to cope with the pain (Kerns, Wagner, Rosenberg, Haythornthwaite, & Caudill-Slosberg 2005). It is not known how pain related fear of movement/(re)injury and psychological distress is associated with

readiness to adopt a self management approach to pain. Treatment in a readiness to change perspective, following the stages of change according to the trans-theoretical model, shows that outcome of treatment is a function of what stage the individual was in when the treatment started (Prochaska, DiClemente, & Norcross 1992). In this perspective it seems important to detect patients who hold beliefs about accepting a personal responsibility to pain management. An improved management of pain related fear presumably will make it easier for patients to continue physical activity, thus avoid pain impairment.

1.5 Physical Activity

One of the problems in research on physical activities and exercise is the different ways of conceptualizing physical activity, and how it is assessed. The World Health Organization's (WHO) classification on functioning (ICF) refers to activity as "the execution of a task or action by an individual (Verbunt, Huijnen, & Koke 2008). Activities of daily living include activities for managing everyday life, like getting out of bed, housework, shopping and many others. WHO defines physical activity as "any bodily movement produced by skeletal muscles that result in a substantial increase over the resting energy expenditure" (Verbunt, Huijnen, & Koke 2008). This makes walking, doing household tasks, combing your hair and running a marathon suitable for the definition of "physical activity". Thus, a distinction between *physical activity* and *physical exercise* is needed.

The WHO defines physical exercise as a particular type of physical activity that is not incidental but planned and structured with the aim of improving or maintaining various aspects of physical fitness (Verbunt, Huijnen, & Koke 2008). Exercise may be categorized as a subcategory of physical activity, an activity that is planned, structured, repetitive, and purposive in the sense that improvement or maintenance of one or more components of physical fitness is an objective (Caspersen, Powell, & Christenson 1985).These definitions of exercise do not require the achievement of a specific level of fitness, only that the intention of exercise is to improve or maintain physical fitness. As Caspersen (1985) points out: "the maintenance or improvement

may be an intermediate objective, and the individual does not need to be continuously aware of it" (Caspersen, Powell, & Christenson 1985). Physical exercise will thus imply different efforts and activities for different people, depending on their health status and physical fitness. Using these understandings of physical activity and physical exercise, the difference between physical activity and physical exercise lies in the purpose of the activity and if the activity maintains or improves physical fitness. Still, to many people the distinction is blurred (Johnson, Tillgren, & Hagstromer 2009). When a person is bicycling to work – is that physical exercise or physical activity? To most peoples' everyday life this is not a problem, but in research including physical activity as an outcome or a predictor the un-clarity of the different constructs may render assessment of activity challenging (Verbunt, Huijnen, & Koke 2008).

The conceptualization of movement and physical activity as behavior which brings energy expenditure (the energy cost of the behavior) constitutes different methods of assessing physical activity (Ainsworth 2009). Direct methods include motion sensors as pedometers and accelerometers which provide optimal accuracy when measuring movements as they occur (Ainsworth 2009). However, these devices may be difficult to use in clinical settings, and they will never measure all aspects of general activity. Indirect methods include self reports, like diaries and questionnaires. Several well evaluated standardized questionnaires as well as researcher prepared questions and patients' diaries exist (Verbunt, Huijnen, & Koke 2008).

Physical activity is known to have a positive impact on peoples' health (Pedersen & Saltin 2006). In Norway, the general belief has been that Norwegians are very physically active, taking part in sports and out-door activities. However, the level of physical activities has decreased in Norway, as in the rest of the industrialized world, and in 2005 the Department of Health and Care launched the "Action plan on physical activity 2005 – 2009" (Handlingplan for Fysisk Aktivitet 2005-2006). The objective of the action plan is to limit factors which create physical inactivity and to promote physical activity in the population (Ministry of Health and Care

Services 2005). In the Action plan it is stated that there is a need to strengthen the research field of physical activity and health. The aspects mentioned include knowledge about how different activity modalities influence health, behavioral and motivational factors related to physical activity and the relationship between physical activity and different diseases (Ministry of Health and Care Services 2005). Chronic muscular pain is one of the diseases known to benefit from physical activity, and research in this area is needed and encouraged.

1.6 Activity related pain

It is a common clinical observation that many patients with chronic musculoskeletal disorders report pain during exercise or even with light muscle work during general activity. The mechanisms behind this sensibility are not fully known. It is suggested that pathological processes and pain may result in adaptive or protective altered motor behaviour in response to pain (O'Sullivan 2005). This means that the individual in pain starts moving in such a way that pain is avoided or minimized, or the painful body area is protected. One example is the limping-like walking in patients with low back pain or the avoidance of lifting arms in patients with neck/shoulder pain. This type of maladaptive moving may also be related to stress, fear and somatisation (O'Sullivan 2005). There is some evidence that fear of movement/(re)injury negatively influences physical performance and pain in experimental studies (George, Dover, & Fillingim 2007;Vlaeyen, Kole-Snijders, Boeren, & van 1995).

Activity related pain, as well as psychological factors, have been shown to be associated with different stages of chronic pain (Brox, Storheim, Holm, Friis, & Reikeras 2005). Reported pain on activity, psychological distress and fear avoidance appears to be higher and the sense of self efficacy weaker in patients groups with longstanding pain compared with patients with subacute pain (Brox, Storheim, Holm, Friis, & Reikeras 2005). It is also suggested that pain induced by physical activity is of a different nature than chronic muscular pain, and is conceptualized as a sort of

acute pain (contraction pain) within a chronic pain course (Vollestad & Mengshoel 2005). Following this argument, pain during exercise with high impact on muscle work may be of a different nature – and maybe a different experience – from increased pain during general activity which do not require much muscle work.

Hypothetically, anxious persons who interpret pain as dangerous are likely to be hyper- vigilant to pain signals and focus on pain during activity, thus perceiving increased pain (Arntz, Dressen, & Merckelbach 1991). Earlier experiences with painful activities and expectations about impending pain may also interfere with pain perception during exercise and other general activities (Gatchel, Peng, Peters, Fuchs, & Turk 2007). There is fair evidence that pain related fear and anxiety increases pain, psychological distress and physical disability while pain coping strategies and readiness to change decrease pain, psychological distress and physical disability (Keefe, Rumble, Scipio, Giordano, & Perri 2004). The role of these factors in activity related pain will be a subject of investigation in this thesis.

1.7 Aims of the study

The main objective of this study was to investigate the occurrence and patients' experience of increased pain during physical activity.

Specific aims of the study were:

- To explore the association between activity related pain and fear of movement/(re)injury, psychological distress, pain self efficacy and pain variables.
- To investigate if fear of movement/(re)injury and psychological distress were associated with pain during exercise and general activities in individuals with non-elevated level of psychological distress.
- To explore by Rasch analysis the internal construct validity of the Norwegian form of the Tampa Scale of Kinesiophobia.
- To explore and gain further understanding of pain related to physical activity and fear, in the context of daily living and from the patients' perspectives

- To evaluate the ability of the Pain Stages of Change Questionnaire to classify subjects with chronic pain into specific profiles of readiness to adopt a self management approach to pain, and describe the association between stages and the individuals' fear of movement/(re)injury, psychological distress and pain self efficacy.

1.8 Ethical considerations

Participants in this study were outpatients at a hospital clinic. Their reason for seeking medical care was their pain situation. It is thus important that patients are aware that participating in a research study is not mandatory. Any pressure on patients to feel obliged to participate should be reduced and patients were informed that participating is voluntary. Guidelines from the Regional Ethics Committee suggested that patients in this study should not be invited to participate by the person who treated them, or in a treatment situation. This advice was followed, and there was no interaction between the researcher and the patients at the moment of giving informed consent. The study was approved by the Regional Ethics Committee and permission was obtained from the Norwegian Social Sciences Data Service. Written informed consent was a prerequisite to participation.

2. PARTICIPANTS AND METHODS

2.1 Design

In this study an explorative design inspired by a mixed method approach was developed (Morse 2003). The choice of methods was concept driven and data from the four studies were analyzed separately. Survey studies were the bases for papers 1, 2 and 4. Paper 1 investigated the validity of the TSK, and paper 2 explored activity related pain and its relation to psychological and other factors. During preparation and analysis of questionnaires in papers 1 and 2 several issues and questions arose, and a need for different perspectives became evident in order to gain better understanding of activity related pain and pain related fear of

physical activity. Thus, in paper 3, a qualitative interview study was established. In paper 4 profiles of subscale scores of the PSOQ were identified and the psychometric characteristics of subjects in the different stages were analyzed. An overview of methods for data collection and analyses is given in table 2.

2.2 Participants

Participants were recruited from patients referred to the Neck and back unit at the Dept. of Physical Medicine and Rehabilitation at the University Hospital of Northern Norway in the period October 2005 through October 2006. The unit receives patients referred from primary health-care with various musculoskeletal complaints (ICD 10 diagnosis M00-M99). Five hundred and forty nine patients were referred during this period and were invited to participate. Two hundred and sixty three patients gave informed consent and met the inclusion criteria. After leaving out incomplete questionnaires, the number of participants was reduced to 120 in study 1, two hundred and thirty two in study 2 and 184 in study 4. Ten patients participated in study 3. Demographic data on participants in the four studies are given in Table 1.

Table 1 Demographic and descriptive pain data of participants in the different papers.

	Paper 1 N = 120	Paper 2 N = 232	Paper 3 N = 10	Paper 4 N = 184
Age, years (SD)	42 (10)	42 (10)	31- 51	41,5 (9.8)
Female (n) Male (n)	52 % (62) 48 % (58)	53 % (124) 47 % (108)	5 5	53 % (95) 47 % (89)
Marital status Married (n) Cohabitants (n) Single (n)	 50% (60) 25% (30) 25% (30)	 44 % (102) 23 % (54) 32 % (76)	 6 4	 43 % (78) 27 % (50) 30 % (56)
Education: Primary school (n) High school (n) Vocational training (n) University/college (n)	 23 % (28) 11 % (13) 39 % (47) 27 % (32)	 20% (46) 12 % (26) 40 % (92) 28 % (65)	 2 5 3	 19 % 11 % 40 % 30 %
Main pain problem: Low back/leg pain (n) Neck/shoulder/arm(n) Multiple pain sites (n)	 40 % (48) 60% (72)	 47 % (110) 31 % (73) 22 % (49)	 5 3 2	 45 % (82) 30 % (56) 22 % (40)
Duration of pain. < 6 months 7 – 12 months 13 – 60 months 61 – 119 months >120 months	 All patients had pain for more than 6 months	 0.5% (1) 10 % (22) 47 % (101) 20 % (43) 23 % (50)	 1 2 2 5	 9% (17) 49% (85) 18 % (31) 24 % (42)

2.3 Data collection and analysis

As shown in Table 2 data in papers 1, 2 and 4 were based on standardized and self-reported measures and questionnaires concerning pain, physical activity and pain-related fear of movement/(re)injury. The data in paper 3 was based on qualitative interviews.

Table 1 Methods of data collection and analysis in the four papers.

Paper	Data collection	Data analysis
1	Standardized Questionnaires	Statistics: Rasch Analysis T-test, Anova
2	Standardized Questionnaires. Self-report Questionnaire	Statistics: Logistic regression, T-tests.
3	Interviews, Tape recorded	Qualitative text analyses.
4	Standardized Questionnaires	Visual inspection Statistics: Cluster analysis Anova, Chi-square tests

2.4 Measures

An overview of measures used in the different papers is presented in Table 3.

Pain intensity was measured by a numeric rating scale (NRS), which has been found a valid measure of pain intensity (Grotle et al., 2004). Patients were asked to mark on a scale from 0 (no pain) to 10 (worst pain imaginable) how much average pain they had had during the last week. There were one scale for “pain during rest”, and one scale for “pain during activity”, and patients were asked to mark one score on each scale. (*Papers 1, 2 and 4*)

Increased pain during activity

Increased pain during activity was assessed in two ways. One was by subtracting each subject’s score on the numeric rating scale for ‘pain at rest’ (NRS) from the score for ‘pain during activity’ (NRS) .The presence or absence of pain on activity was operationalized by self reports where the responders answered “yes” or “no” to the question whether they experienced increased pain during general activity or exercise, in case they exercised or used to exercise.

Spread of pain

Spread of pain was assessed by drawings from the Norwegian version of the McGill Pain Questionnaire (Strand & Wisnes 1990). On the drawing of the front and back of the body a total of 100 squares cover the whole body surface. The respondents were asked to shade the squares covering a painful area. Shaded squares were counted to measure the spread of pain. *(*papers 1, 2 and 4*)*

Pain location

Based on the clinical examination as well as the pain drawings the participants’ pain locations were categorized as: neck / shoulder / arm pain, low back / leg pain and multiple pain sites.

Exercise

To identify subjects who exercised, respondents were asked if they exercised or not (yes/no), and they were asked to describe their exercise by marking: Strength training, (like lifting weights), endurance training (like running and biking), or a combination. *(*papers 2 and 3*)*

Level of physical activity

The level of physical activity was assessed by a questionnaire reflecting levels of leisure time physical activity (Borodulin et al. 2008;Leren et al. 1975). The questionnaire has four response options, and respondents are asked to mark the best fitting expression from “totally disagree” to “totally agree”. The options are: (i) In my leisure time I mostly read or watch television, (ii) I walk, cycle or move in other ways at least 4/h per week, (iii) I exercise to maintain my physical condition, do heavy garden work or other heavy activities at least 4 h/week, and (iv) I regularly practice hard exercise or competitive sport. (paper 2)

Pain related fear of movement/(re)injury

The Tampa Scale of Kinesiophobia (TSK).

Fear of movement/(re)injury was assessed by the Tampa Scale of kinesiophobia (TSK), a 13-item questionnaire aimed at assessing fear of pain and re-injury due to movement. Each item is provided with a 4 points Likert scale with scoring alternatives ranging from “strongly disagree” to “strongly agree” (Vlaeyen, Kole-Snijders, Boeren, & van 1995). The TSK has been found to be a valid and reliable instrument, with a unidimensional underlying construct, and the Norwegian version of the questionnaire has been validated (Damsgard et al. 2007;Haugen et al. 2008;Roelofs J et al. 2004). Cut-off scores for TSK have not been established and vary within research (Lundberg et al. 2006). (papers 1, 2 and 4)

Fear avoidance beliefs

The fear avoidance beliefs questionnaire (FABQ)

The FABQ consists of 2 scales: 5 items focus on fear avoidance beliefs of physical activity and 11 items focus on fear avoidance beliefs of work (Waddell, Newton, Henderson, Somerville, & Main 1993). The scoring options are on a six level Likert scale rating from ”totally disagree” to “totally agree”. Range of the score is 0-96. The possible range for FABQ “physical activity” is 0 to 30 and for FABQ work it is 0 to 66 (*Paper1*).

Psychological distress

Hopkins symptoms check list 25 (HSCL 25).

Psychological distress was assessed by the Norwegian version of HSCL 25 (Derogatis et al. 1974;Sandanger, Moum, Ingebrigtsen, Dalgard, Sorensen, & Bruusgaard 1998). The questionnaire contains 25 questions comprising the dimensions of depression, anxiety and somatisation. The three factors are interrelated and the items measure an overall clinical distress variable (Elliott, Fox, Beltyukova, Stone, Gunderson, & Zhang 2006). The items are scored on a 4 points Likert scale rating from “not at all” to “very much”. The scores of the items are summed and then divided by 25. HSCL has been found to be a valid instrument, with a suggested cut- off score of 1.70 (1.75 for males, 1.66 for females) (Sandanger, Moum, Ingebrigtsen, Dalgard, Sorensen, & Bruusgaard 1998) (papers 1,2,and 4).

Self efficacy

Arthritis self efficacy scale (ASES) (the self efficacy for pain subscale).

Self efficacy was assessed by the ASES, a measure of perceived self efficacy to cope with chronic pain, originally developed for patients with rheumatoid arthritis (Lorig et al. 1989). ASES comprises three subscales; self efficacy for pain, function and ability to influence symptoms. A Norwegian version of the ASES self efficacy for pain subscale has been used in several back pain related studies, and a Swedish version has been validated (Lomi 1992). The scoring options for the self efficacy for pain subscale were on a 6 level Likert scale ranging from “totally disagree” (0) to “totally agree” (6) with a possible raw score for each of the five questions, from 0 to

6. The scores for the 5 items are summed and then divided by 5, which gives a possible range from 0 to 6 (*Papers 2 and 4*).

Readiness to change

The pain stages of change questionnaire, PSCOQ

A 30-items questionnaire that measures to which extent an individual considers making behavioural changes to cope with pain, and also an individual's acceptance of personal responsibility for pain control (Kerns, Rosenberg, Jamison, Caudill, & Haythornthwaite 1997). Each item is provided with a 5 points Likert scale with scoring alternatives ranging from "strongly disagree" (1) to "strongly agree" (5). This gives a possible total raw score range from 30 to 150. The items represent the four stages of change from the trans theoretical model (TTM): Precontemplation (7 items) with a range from 7 to 35, contemplation (10 items) with a range from 10 to 50, activation (6 items) with a range from 6 to 30 and maintenance (7 items) with a range from 7 to 35. Raw scores are transformed into a mean score for each stage/ subscale (paper 4).

Table 3. Measurements in the four papers.

Measure	Paper
Pain intensity, NRS	1, 2, 4
Pain Increase During Activity, NRS	2
Spread of pain (Drawing)	1, 2, 3*
Exercise habits (Self report)	2, 3*
Level of leisure time physical activity (Self report)	2
Fear of movement/(re)injury (TSK)	1, 2, 4
Fear Avoidance beliefs (FABQ)	1
Psychological distress (HSCL 25)	1, 2, 4
Pain Self efficacy (ASAS)	2, 4
Pain Readiness to change (PSCOQ)	4

*Data from these measures were used when selecting participants for paper 3

2.5 Data analysis and statistics

2.5.1 Rasch analysis (paper 1)

This paper is based on data from questionnaires collected in the period from October 2005 through March 2006. 120 patients, mean age 42 (SD10) participated in the study. Participants were classified as patients with low back pain (n = 48, female 42 %) or widespread pain (n = 72, female 58 %), according to their pain drawings and score on the NRS.

Rasch analysis was used to explore the measurement properties of the Norwegian version of TSK. Other analysis (t-tests, Chi squares, One way Analysis of Variance, Principal Component Analysis) were performed by SPSS for windows, version 13.0.

The Rasch model is based on the assumption that the probability of a person affirming a trait in an item of a questionnaire depends on: a) the level of the actual trait in the person and b) the level of the actual trait expressed by the particular item in the questionnaire. The Rasch models presume a transformation to an interval scaling and an underlying unidimensional construct. Hence, the scoring options for each item were evaluated by separate thresholds. Chi square item trait interaction statistics were applied and the unidimensionality was evaluated by creating two subsets of items (Principal Component Analysis), consisting of the residuals of the most negative and the most positive values. In addition, these two estimates were compared by Independent T-Tests. The fit of the persons and the items to the Rasch model and its underlying construct were evaluated by Chi-square statistics. To evaluate how well the TSK differentiates between persons with different levels of fear of movement/(re)injury the Person Separation Reliability Index was used. Another important issue was to explore if the TSK was invariant with respect to gender, age and pain areas. This was done by analyzing the differential item function (DIF) using analysis of variance (ANOVA). Gender, level of age (groups above and under the median age of 42) pain areas, both uniform DIF (effect of gender, age and pain area) and non-uniform DIF (Interaction between gender, age and pain area) were analyzed. For details see Statistics in paper 1.

2.5.2 Regression analysis (paper 2)

Paper 2 is based on data collected from questionnaires in the period from October 2005 through July 2006. For descriptive data, and measures see Tables 1 and 3. Exercise habits were assessed by questions: “Do you exercise in addition to general activity? (Yes/no). One dependent variable,” increased pain intensity during activity (NRS)”, was calculated by subtracting the highest score on pain intensity at rest (NRS) from the highest score of pain intensity during activity (NRS). The other dependent variables, increased pain during general activity and increased pain during exercise, was used as a dichotomous measure, where responders defined whether they experienced pain during general activity and (previous or ongoing) exercise.

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SPSS for windows, version 15.0 was used for all analyses. Differences between groups were assessed with T-tests and one way ANOVA. The relationship between different factors was assessed by Pearson’s correlation analysis. Multiple regression analysis explored associations between pain, fear of movement/(re)injury, psychological distress, self efficacy and increased pain intensity during activity (NRS). Logistic regression analysis investigated the likelihood for reporting increased pain during general activity and exercise, given the predictive factors. Logistic regression analysis was carried out for the whole sample, and in a subgroup with non-elevated level of psychological distress. Significance level was set at 0.05.

2.5.3 Qualitative interviews (paper 3)

The aim of the study was by qualitative interviews (Kvale 2001) to explore the participants experience of pain related to activity, and how fear was related to the pain. To get rich data on the patients perspectives, participants were selected for diversity with respect to pain history, pain location and exercise habits (Table 1). At the time of the study six participants were currently in a full time employment; three were on sick leave, one was applying for fifty per cent disability pension and one was on an occupational retraining program. Four had participated in an

exercise/learning group organized by the Dept. of Physical Medicine and Rehabilitation.

Data were collected following an interview guide with thematic questions concerning pain related to activities of daily living, at work and during exercise. The interviews were tape-recorded and transcribed to text by a secretary. The analyses followed principles of qualitative content analyses as described by of Malterud and Graneheim (Graneheim & Lundman 2004;Malterud 2001a). Two authors (ED and TH) first independently read the interviews to get a sense of the whole, and then the texts were discussed and congruence on main themes emerged. Themes in this context were the paramount ideas which permeated the text throughout the analyses. Each interview was then searched for meaning units; phrases or words which represented expressions of the themes we wanted to explore. In this process, we looked for the participants' descriptions and explanations of pain associated with different activities and how fear related to pain was expressed. Meaning units with similar content formed codes, which captured phenomena in one or a few words. The text within the codes was further condensed, meaning that an extract of a statement is made. By searching for patterns, similarities and differences in the text categories were constructed. The categories were investigated within and across interviews and different interpretations were reflected upon and discussed. A preliminary draft of results was read and discussed by all authors. Finally, the raw text was read again to ensure that there was no important information missing in the final analyses. Peer discussions were held with the health professionals at the Dept. of Physical Medicine and Rehabilitation consisting of physiotherapists, physicians and occupational therapists, and with researchers from other professions.

2.5.4 Visual inspection and cluster analysis (paper 4)

This paper is based on data collected in the period October 2005 – October 2006. One hundred and eighty four patients with complete registrations in PSOCQ were included. For descriptive data, see Table 1.

To identify profiles of subscale scores of the Pain Stages of Change Questionnaire (PSOCQ) two approaches was followed: 1) Cluster analysis for each of the 184 patients, a profile of mean subscale score was drawn. 2) Visual classification of individual profiles performed by two of the authors. Both cluster profiles and individually drawn profiles were compared with the five profiles earlier identified by Kerns et al (Kerns, Wagner, Rosenberg, Haythornthwaite, & Caudill-Slosberg 2005).

SPSS for Windows version 15.0 was used for analysis. Raw scores of the four subscales of PSOQ were transformed into T-scores. Cluster analysis with Ward's method and a 5-cluster solution was performed. For comparison of groups of data simple cross tabulations (Chi-square tests) were performed. One way analysis of variance (ANOVA) were performed with profiles as the independent variable, and the psychometric scales as the dependent values. The significance level was set at set at 0.05 and Bonferroni corrected with respect to multiple testing.

3. **SUMMARY OF RESULTS**

3.1 The Tampa scale of Kinesiophobia: A Rasch analysis of its properties in subjects with low back and more widespread pain **(paper 1)**

Paper 1 focused on the internal construct validity of the Norwegian form of the Tampa Scale of Kinesiphobia (TSK). The Norwegian form of the Tampa Scale of Kinesiophobia (TSK) was found to be a well targeted, unidimensional instrument. Both items and person responses fitted the Rasch model. The items 1, 2 and 4 showed reversed probability thresholds. In these items the threshold was lower for Likert scale 2 than 1. Thus the items were re-scored with Likert scale 1 and 2 as the same category. In general the items were found to fit the model. The person fit to the model was good (- 0. 17, SD 1.15), person separation reliability 0.87. Items and subject were well distributed along the logit distribution. On average a lower level of

fear of movement/(re)injury was scored by the subjects. The threshold between “Strongly agree” and “Some agreement” in item nr 11 (“I am afraid that I might injure myself if I exercise”) reflected the highest degree of fear of movement/(re)injury. No uniform DIF was found except for one item (Nr 10: “It is not really safe for a person with a condition like mine to be physically active”), which varied across gender. Men were more likely to agree on this statement. Non-uniform DIF was not found.

3.2 Activity related pain in patients with chronic musculoskeletal disorder (paper 2)

Paper 2 focused on the occurrence of pain related to exercise and general activity and the association between such pain and psychological factors and pain. Increased pain during activity (NRS) was reported by 69 % (n = 160) of the respondents, at a mean value of 2.5 (SD 1.6). Sixty seven per cent reported that they exercised, 58 % of them reported increased pain during exercise. Pain during activity was significantly lower ($p = 0.03$) among participants at the highest level of physical activity compared with those at moderate and low levels of activity. Fear of movement/(re)injury was a common positive predictor for increased pain intensity during activity (NRS) ($p < 0.001$) and for the likelihood of experiencing pain during general activity and exercise ($p < 0.001$). The likelihood of experiencing pain during general activity was also positively associated with a large pain distribution ($p < 0.001$), while the likelihood of pain during exercise was negatively associated with a higher sense of pain self efficacy ($p < 0.001$).

The level of psychological distress in the study sample (n = 232) was elevated (Mean 1.79, SD 0.48). Psychological distress was not significantly associated with reporting increased pain during activity, and fear of movement/(re)injury remained a significant predictor for the likelihood of reporting increase pain during activity also in a subgroup with non-elevated level of psychological distress ($p < 0.001$, OR 1.09 95 % CI 1.05 – 1.13) and during general activity ($p < 0.001$, OR 1.07 95 % CI 1.03 – 1.12).

Staying active despite pain. Activity related pain and pain beliefs among out patients with musculoskeletal pain (Paper 3)

Paper 3 focused on how patients with musculoskeletal pain described and explained pain related to activities, like exercising, activities of daily living and work. The participants described pain related to activity and in general as a "signal from the body" with diverse meanings. Initially it was a sign of danger, but with the influence of time, it changed to a signal to move or calm down. Pain related fear of physical activity and fear of being injured seemed to decrease with time, as the patients learned how to manage pain and re-interpreted its meaning. Own bodily experiences and learning from self and others contributed significantly to the patients' understanding of their pain and how to manage it. To these participants, who had suffered pain for more than one year, the most frightening aspect of pain was its possible prediction of a bleak future. The participants made an effort to stay active despite pain. Their wish to stay active seemed to be grounded in their view of physical activity as healthy and fun, and that activity was the key to participate in different social situations and roles. To stay active despite pain attending to and interpreting the pain signal and thus regulating activity was an ongoing procedure. This required calculating and planning, which became a part of everyday life. Depending upon the nature of the activity, they sometimes chose pain as an acceptable risk.

3.4 Readiness to adopt a self management approach to pain – are profiles of subscale scores on the Pain Stages of Change Questionnaire useful? (paper 4)

Three distinct profiles were identified visually as well as by cluster analyses. These were:

(i) Precontemplation profile (Subjects feel little control over a strictly physical pain problem. Pain is a signal of damage that necessitates decreased activity), (ii) Contemplation profile (Subject believe that their pain problem is up to them to solve. They perceive moderate control over pain and moderately believe that activity

should be avoided) and (iii) Participation profile (Subjects perceive themselves in control over pain. They are active and do not believe that pain is a signal that necessitates decreased activity). Two of these profiles appeared to have distinct and opposite psychometric characteristics. Individuals with less readiness to take personal responsibility for pain (precontemplation profiles), reported most psychological distress, least self efficacy of pain and statistically significantly higher fear of movement/(re)injury than in individuals with more accept of personal responsibility to manage pain (Mean 27.5, SD 6.6) ($p < 0.01$). The level of pain intensity during activity was higher in participants with less readiness to take a self – management approach to pain (precontemplation profiles) (mean 7.8, SD 1.6) than in subjects who were more acceptant towards self – management (participation profiles) (mean 6.7, SD 6.2), but was not statistically significant after Bonferroni corrections ($p=0.04$, Bonferroni corrected significance level 0.02).

4. DISCUSSION

4.1. Methodological considerations.

Discussion of methods is presented in the different papers, thus the methodological considerations will focus on issues concerning self-reports and the approach of mixing qualitative and quantitative data.

4.1.1 Self reports

There are several possibilities when choosing methods to study peoples' experiences, beliefs and behaviors. In this study, all data were collected by standardized questionnaires, self report questions made by the researchers or tape recorded qualitative interviews. One potential problem in surveys is "the social desirable response bias" (Polit & Hungler 1999a) which refers to some individuals tendency to respond to questions from a particular perspective, to answer in a socially acceptable way (Cozby 2007). One example in our study was the questionnaire about leisure time physical activity, where one alternative answer was: "I spend most of my spare time reading or watching TV". In a culture where

appearing active is important, this statement may be perceived as stigmatizing. It is an answer alternative that might be difficult to choose, even if it is the most correct one. However, it should not be assumed that people misinterpret themselves (Cozby 2007). Participants' anonymity and thorough and clear information about the project and its goals is considered important to get honest answers (Cozby 2007). Participants in this study received written information before answering the questionnaires. Still, one cannot ignore the possibility that some questionnaires have been misunderstood or biased. The biasing factor may also result from some individuals' way of expressing themselves in extremes ("Strongly agree") (Polit & Hungler 1999c). Additionally, in this study procedures for separating treatment from research were strongly recommended by the ethical committee in order not to put pressure on patients to participate. It is possible that this procedure has lowered the response rate and contributed to selection bias, as the attendees in the present study is of higher education than the non-attendees. However, selection bias is common in survey studies; and non-attendees are characterized by being young, males, and have lower income and educational level than attendees (Sogaard et al. 2004). Interestingly, and in contrast to these common characteristics, attendees in this study consisted of more males than non-attendees

4.1.2 The use of qualitative and quantitative data.

There are certain differences between qualitative and quantitative research, which may complicate the use of the two approaches in the same study, but which can also provide a broader understanding of the explored phenomena (Marshall 1996;Morse 2003;Polit & Hungler 1999b). Differences address the philosophical foundations, and thus the research questions relevant for the two disciplines (Marshall 1996). The foundation for quantitative approaches is deductive and reductional and aims to test pre-set hypothesis, which may be generalized to other populations. The foundation for qualitative methodology is inductive and aims to explore complex human issues through an iterative and flexible process. Results from qualitative research cannot be generalized, but may be an issue of transferability. Thus, quantitative methods are suitable for the question "what?",

while qualitative methods are suitable for the “why?” and “how?” questions (Marshall 1996).

The possible problems in combining qualitative and quantitative research are reflected in the discussion about the different ontological and epistemological positions of the two research traditions (Teddlie & Tashakokori A 2003). However, within health research, such as medicine, nursing and rehabilitation, mixed method research has earned increasing accept and is encouraged (Foss & Ellefsen B 2001;Malterud 2001b;Ohman 2005;Sandelowski 2000). The arguments for using mixed method techniques more or less include the paradigm discussion. While some take a pragmatic position (Polit & Hungler 1999b) others argue the need for a new comprehensive epistemological position, as nursing (and other health care sciences) are characterized by complexity (Foss & Ellefsen B 2001). In this study the qualitative data were used complementary to further explore data on activity related pain and pain related fear reported by participants in a survey (papers 1,2 and 3) (Polit & Hungler 1999b;Sandelowski 2000). The four studies were analyzed separately and there were no synthesizing analyses of data, but data from the four papers were studied for an expanded understanding of activity-related pain and pain related fear of physical activity.

Albeit our pragmatic approach to using both quantitative and qualitative methods, some challenges emerged. As the researcher is the instrument in qualitative research; awareness of his or her preconditions are important aspects throughout the research process (Sandelowski 2000). In this case, the perception of patients with musculoskeletal pain as physically inactive was one of the preconditions which actually contributed to the raise of the research questions in paper 3. In addition, data from paper 1 and 2 together with the fear avoidance theory were parts of what formed the preconditioned “spectacles” to the analyses of data in paper 3. The theoretical underpinnings in the quantitative studies, and the bases for the questionnaires, were that fear of movement/(re)injury, psychological distress and self efficacy are phenomena that exists. However, they are theoretical constructs,

operationalized by questionnaires for individuals to answer; thus presenting with these phenomena to a certain extent. When for example the Hopkins Symptom Check List indicated that the participants presented with an elevated level of emotional distress (with a cut off value that is also a theoretical construct) the impression, and our preconditions were that the participants were distressed persons (paper 2). Hence, it was challenging through the qualitative study to be flexible and open to a different understanding of the participants' experiences. But, also of importance is that the results from the qualitative interviews shed light on the interpretation of results from the quantitative survey. For example, knowing how participants described a different perception between pain during exercise and pain during work, and how participants re-interpreted pain signals (paper 3) initiated discussions about whether and how exercise may be different from general activity, and how fear of movement/(re)injury could be understood in alternative ways; as a response to what your body tells you. In this way the qualitative data enriched and elucidated findings from the quantitative studies, and have implied some possible answers to the "how" and "why" questions raised during the work on the surveys.

4.2 Pain related fear

4.2.1 Perspectives from the quantitative analyses

To assess pain related fear of movement/(re)injury the TSK was used. The questionnaire has been validated in several studies, and factor analysis has been used to identify psychometric properties in the questionnaire. Clarifications on the concept have been requested (Lundberg, Larsson, Ostlund, & Styf 2006). At the time when our study was conducted literature on factor analysis of TSK revealed varying factor structures, with from one to five factors (Burwinkle, Robinson, & Turk 2005;Goubert et al. 2004;Lundberg M, Styf J, & Carlsson F 2004;Roelofs J, Goubert L, Paters M, Vlaeyen J, & Crombez G 2004;Vlaeyen, Kole-Snijders, Boeren, & van 1995). This raised the questions whether factor analysis was the proper way to investigate the eventually underlying construct of this instrument. The factors identified may be more or less correlated, but idealistically a questionnaire should capture one unidimensional phenomenon (Polit & Hungler 1999a). The items in TSK

are scored on ordinal scales and the Rasch analysis offers a possibility for transformation into interval scaling (Andrich D 1978). Even though there has been some debate about the Rasch method of validating questionnaire (Pedraza & Mungas 2008), it is increasingly used in medical research (Tennant, McKenna, & Hagell 2004). In the present study it was used to get an impression of whether fear of movement/(re)injury, as measured by the TSK, is a unidimensional construct, comprising both the individuals' fear of pain and avoidance of physical activity. Furthermore, the analysis revealed that the questions in TSK captured different levels of fear of pain and avoidance. The inconsistency in factor analyses of TSK has raised questions about what it really measures, and it has been suggested that it mirrors a general feeling of vulnerability (Burwinkle, Robinson, & Turk 2005). In our study, psychological distress was found at an elevated level (Table 1), which is consistent with findings in other studies of similar populations (Grotle, Vollestad, Veierod, & Brox 2004), while fear of movement/(re)injury was reported higher than in other studies of patients with musculoskeletal pain (Feleus et al. 2007;Haugen, Grovle, Keller, & Grotle 2008). As anticipated, psychological distress was correlated with fear of movement/(re)injury. However, our study did not reveal psychological distress as a predictive factor for the likelihood of reporting presence of increased pain during exercise and general activity, while fear of movement/(re)injury remained a significant predictor also in a sub-group of subjects presenting a normal level of psychological distress. This could indicate that fear of movement/(re)injury is connected with the pain experience, and reflects a different construct than general anxiety and somatisation. This adds to the conceptualization of the construct of fear of movement/(re)injury. Recent studies presenting Rasch Analysis of the Brazilian version of TSK replicated the findings in our study of The Tampa Scale of kinesiophobia as an instrument assessing unidimensional construct of fear of movement/(re)injury (Siqueira FB, Teixeira-Salmela LF, & Maghalaes LC 2007). However, the 2 factor solution of this questionnaire has also been replicated in a multi cultural study (Roelofs et al. 2007). The latter study supports previous factor analyses indicating that TSK comprises two underlying dimensions which probably are i) pathophysiological beliefs about pain (i.e. interpreting pain as a sign of danger)

and ii) (consequently) activity avoidance. The collected result suggests that the two factors are strongly related: individuals who experience pain as a sign of danger avoid physical activity, which support the identification of a unidimensional construct in the present thesis.

Fear of movement/(re)injury have shown some predictive value for future pain and disability (Boersma & Linton 2006), and appears to be modestly present in individuals with an established self management approach to pain (paper 4). Fear of movement/(re)injury was significantly, but modestly, associated to the likelihood of experiencing increased pain during activity, and thus adds to previous information about this phenomenon (paper 2). It is reasonable to assume that the role of fear of movement/(re)injury is indirect, in the sense that fear enhances focus on pain, and increases perceived pain (Arntz & Claassens 2004). Thus, for patients in pain who experience that pain is increased by physical activity, the activity may be perceived as threatening. Consequently, fear (and thus pain) during activity will increase. However, it is also likely that fear of movement/(re)injury is a consequence of painful activity, and that fear and pain during activity are mutually reinforcing. In paper 3 (see below), pain related fear was one of the phenomena explored in a contextual perspective with qualitative methods.

4.2.2 Perspectives from qualitative analyses

Analysis of qualitative data in a contextual perspective revealed pain-related fear in general and pain related fear of physical activity as complex experiences. Participants described how stressful events and stressful life situations made them more aware of their pain symptoms, but these experiences were not specifically related to physical activity. Pain signals were indeed interpreted as related to emotions, but the emotional connection to the pain sensation appeared to be a way to make sense of pain- what pain tells the individual – and pain signals had various interpretational possibilities. The diverse meaning of everyday pain from patients' perspectives includes pain as a signal of malfunction, but it is also strongly recognized as an experience of emotional and mental as well as physical suffering

(Aldrich & Eccleston 2000). Uncertainty about causes for pain bring fear and stress to patients with chronic pain conditions, thus medical examinations and diagnostic work is important in reducing fear as well as making meaning of pain (Bullington et al. 2003;Jerlock, Gaston-Johansson, & Danielson 2005). Fear of movement/(re)injury as assessed by the Tampa Scale of Kinesiophobia has shown both that the level of fear of movement/(re)injury remains unchanged (Feleus, van, Bierma-Zeinstra, Bernsen, Verhaar, Koes, & Miedema 2007) and that it decreases with time (Vangronsveld et al. 2008). As narrated by participants in our study, the initial fear of pain and activity decreased as they experimented and learned how to manage pain and how to interpret it (paper 3).

Increased pain during physical activity seemed to be more easily tolerated when it was not interpreted as a sign of danger. In agreement with findings in other qualitative research (Parsons et al. 2007), the participants' subjective experiences, as well as objective proof of illness, were important elements on which to base their beliefs and rationale for activity. Pain was experienced as exhausting and unpleasant; a burden in itself even if it was not interpreted as dangerous. Thus, avoiding movement could be a calculated choice. This agrees with findings that adaptive and protective motor behavior develops as a result of (chronic) musculoskeletal pain (O'Sullivan 2005). It is also in concordance with studies showing that individuals with high pain-related fear adopt alternative movement strategies to avoid putting strain on a sore back (Thomas & France 2007). The remaining question is if the avoidance of movement is caused by fear, or if it is rational behavior; perhaps what the individual think to be best or even have been taught? Health care professionals' attitudes and beliefs may unconsciously be signalized and thus brought on to patients in education treatment. Earlier it was usual to warn patients about activity and not to put strain on hurting muscles. Despite a change in rehabilitation treatments towards more active treatment regimens, some of these attitudes are possibly still alive (Linton, Vlaeyen, & Ostelo 2002). Also, as pointed out in the introduction, pain "puts an affective call on us" to escape the painful stimuli, a call which is "built into our nerve system" (Leder D

1990). To accept pain as not dangerous is thus a challenging change for individuals. Individuals who accept self management of pain and are ready to change their everyday life situation to meet such an approach seem to be less characterized by psychological distress and fear of movement/(re)injury and perceive more control over pain (paper 4). It would be of interest to investigate if these characteristics are personal traits and to what extent change may be learned. As presented in paper 3, stories of changing interpretations of pain signals over time permeated the texts from interviews. Embodied experiences and reflections on the contemporary situation in the light of previous experience seem to help people to recognize patterns and eventually change those (Steihaug & Malterud 2008). The personal, embodied experience seems important to recognize patterns and be able to change them (Mannerkorpi & Gard 2003;Steihaug 2007). Thus, changing the meaning of pain from danger to no danger, and to act accordingly, is a challenge which may depend upon personal experience and awareness. The readiness to change seem to differ significantly between individuals (paper 4), and how individuals move between stages in a changing process remains unclear.

4.3 Activity related pain.

4.3.1 Perspectives from the quantitative analysis

The most interesting finding concerning activity- related pain was that as many as 69 % reported increased pain intensity during activity. Yet a majority of the participants reported being physically active, 66 % even reported exercising. Interestingly, in surveys on exercise habits in the general population, 67 % reported exercising in some way (Ministry of Health and Care Services 2005). It is also in accordance with findings showing that patients associate physical activity with well-being and health even if their symptoms were worsened by physical activity (Mannerkorpi et al. 2008).

Based on these findings, one may speculate whether patients with musculoskeletal disorders have changed their physical activities at all due to pain. Research in this area has shown conflicting results, and conclusive evidence of physical deconditioning and disuse in patients with low back pain is still missing (Bousema et

al. 2007;Smeets et al. 2006;van, V & Mierau 2000;Verbunt, Huijnen, & Koke 2008). When assessing physical activity, it is important to be aware of the fact that there may be discrepancies between how an individual perceives his or her level of physical activity and how physical activity in the same individual appears when assessed directly – by objective methods. Likewise, the decrease in physical activity from the period before onset of pain to the period after onset, may be perceived differently by the individual than how it is registered (Verbunt et al. 2005). Both perceived and an actual decline in activity before onset of pain seem more important in the explanation of pain disability in patients with an active lifestyle before onset of pain (Verbunt, Sieben, Seelen, Vlaeyen, Bousema, van der Heijden, & Knottnerus 2005). For sedentary patients, the daily activity schedule probably is less influenced by pain. As the present study was cross-sectional it was not possible to determine whether the participants changed their exercise habits or level of leisure time physical activity over time. In a longitudinal study, Bousema and colleagues (2007) found that a majority of the patients did not decrease their activity level after onset of pain – the activity level was in fact increased for half of the population (Bousema, Verbunt, Seelen, Vlaeyen, & Knottnerus 2007). The present study contributes to the literature by illustrating that individuals with chronic musculoskeletal pain seem to stay physically active despite pain. However, a possible association between pain intensity and physical activity level is indicated as the participants at the highest level of physical activity reported least pain during activity. The association between level of pain and capacity reduction have shown various results, depending on the capacity task used to assess the capacity (Smeets et al. 2007). While level of pain was significantly associated with walking and stair climbing, it did not explain variance in a lifting task when gender, depression and fear of movement/(re)injury were included in analyses (Smeets, van Geel, Kester, & Knottnerus 2007). Apparently, there are controversies concerning the role of level of pain, as well as methodological difficulties in assessing pain and physical activities.

In the present study, 69 % of the participants described increased pain during activity, which means that they were rarely free of pain, unless pain is mainly

connected with activity. If the pain intensity was not perceived as too disabling, that might have been one reason for participants in this study to be able to stay physically active. A possible way of coping is to continue activities, but to change the intensity or the manner of executing the activity. The indication of a higher level of pain during activity, as measured on NRS, reported among individuals with less readiness to self-management of pain (paper 4) might reflect the burden of pain as a barrier to take one's own responsibility for pain management.

However, viewing pain as a bio-psycho-social experience necessitates the inclusion of different factors when exploring pain related to activity. The previously mentioned studies on physical activity supported the role of psychological and behavioural factors in pain disability and physical performance (Verbunt, Sieben, Seelen, Vlaeyen, Bousema, van der Heijden, & Knottnerus 2005;Verbunt, Huijnen, & Koke 2008). Depressive mood and fear of movement/(re)injury was a predictive factor for perceived and actual decline in physical activity, and perceived activity decline plays a mediating role in the association between fear of movement/(re)injury and disability (Bousema, Verbunt, Seelen, Vlaeyen, & Knottnerus 2007;Verbunt, Sieben, Seelen, Vlaeyen, Bousema, van der Heijden, & Knottnerus 2005). In our study, a high level of fear of movement/(re)injury was a common predictive factor for increased pain during both exercise and general activity, while in this model psychological distress was not associated to increased pain in any of these activity situations. Participants with less readiness to self-management of pain presented with higher levels of pain during activity (though not statistically significant) and more fear of movement/(re)injury and psychological distress (paper 4), which agrees with other findings of a relationship between pain during activity and psychological distress (Brox, Storheim, Holm, Friis, & Reikeras 2005). Thus, high levels of psychological distress may be a mediator to fear of movement/(re)injury in individuals experiencing increased pain during activity.

The significance of the participants self efficacy is in line with previous research in this area (Arnstein, Caudill, Mandle, Norris, & Beasley 1999;Arnstein 2000;Keller,

Brox, & Reikeras 2008;Reneman, Geertzen, Groothoff, & Brouwer 2008). However, a possible differentiation between the pain experience related to general activity and exercise was suggested as self efficacy was a significant predictor only for pain during exercise (Paper 2). Exercise may be perceived different than general activities because it is often associated with pleasure and a healthy lifestyle (Paper 2) (Mannerkorpi, Rivano-Fischer, Ericsson, Nordeman, & Gard 2008). Also, exercise may require more muscle work than activities of daily life. Consequently, patients who reported less perceived control over pain (low sense of self efficacy) seemed more likely to experience pain during exercise and less ready to take personal responsibility of pain management (papers 2 and 4). This raises questions whether the low sense of control over pain is one explanation of why some people do not have sufficient energy to manage by themselves, and perceive increased pain during exercise. As shown in paper 3, a contextual perspective was helpful in order to establish further exploration of activity related pain.

4.3.2 Perspectives from the qualitative analyses

The qualitative study added information about activity-related pain by providing a detailed description of the participant's reasons for staying active despite pain. The findings from the interviews indicated that pain had contextual aspects as participants were able to differentiate between pain during exercise and pain in other situations such as related to work. Exercise and other leisure time physical activity were described as beneficial and/or pleasant, and for some participants, pain during exercise was a familiar experience which did not normally provoke fear. One interpretation of this finding is to regard exercise and leisure time physical activity as an opportunity for the patients to "rest", where pain is anticipated and controllable in a well-known context. A recent study shows that patients describe perceived physical and mental relaxation and enhanced well-being following exercise as significant experiences, despite increase of symptoms during and after exercise (Mannerkorpi, Rivano-Fischer, Ericsson, Nordeman, & Gard 2008). The well-being in this context have been connected with the feeling of becoming stronger and more physically fit, whereas a high level of pain negatively influenced the experience of

relaxation (Mannerkorpi & Gard 2003). In agreement with our findings, the majority of participants believed that physical activity was important for their health, regardless of their level of pain (Mannerkorpi, Rivano-Fischer, Ericsson, Nordeman, & Gard 2008). Mannerkorpi and associates ties a cultural aspect to this finding, as they state that ”The notion that physical activity is important for health is well incorporated in our society”. They further raise the question of whether participants express their individual beliefs and values or whether they express generally held notions of physical activity as good for health (Mannerkorpi, Rivano-Fischer, Ericsson, Nordeman, & Gard 2008). The same question is relevant in this study, and was discussed in the methodological consideration section.

Staying active despite pain was the main theme found in this study (paper 3). These findings are in contrast to those in a study on fibromyalgia, where some respondents had given up many of their daily life activities and were living sedentary lives, including bed rest for much of the time (Mannerkorpi, Kroksmark, & Ekdahl 1999). One possible explanation of this difference is that patients in our study did not experience as much or as widespread pain as the fibromyalgia patients. This perspective is further explored when activity restrictions due to pain are discussed in the context of the nature of pain (Carnes & Underwood 2008). A difference between “ache” and “pain” is described, as “ache” was a sense one can distract oneself from, while “pain” was a barrier to activity (Carnes & Underwood 2008). The distinction between “ache” and “pain” may be fruitful in the understanding of how some patients may experience increased pain during activity. In Carnes’ study, the functional consequences pain had on daily living were important. Help-seeking behaviour changed as pain progressed from “ache” to “pain”, in the sense that the increasing pain brought increasing loss of function and subsequently led to need for help (Carnes & Underwood 2008). This perspective supports the important role of perceived pain in activity restrictions in patients with chronic musculoskeletal disorders. It also emphasises how pain is an important factor why individuals no longer feel able to manage pain by their own coping capacity. Also, it agrees well with the findings that pain intensity is highest in patients who are not ready to adopt

a self management approach to pain (paper 4). Cultural differences are described concerning beliefs of patient's responsibility for own pain and for changing pain behaviour (Bates, Rankin-Hill, & Sanchez-Ayendez 1997). The Anglo cultural way of viewing self- responsibility of health is relevant also in our Scandinavian culture, and behavioral change programs in patient education and rehabilitation adhere to this approach (Bates, Rankin-Hill, & Sanchez-Ayendez 1997). Hence, expecting patients to attend a self-management approach to pain is a culturally biased way of dealing with a pain problem. Culture is also an important context when viewing pain as a cost of participation in different social situations, and the importance of the activity and the situation as conclusive for tolerating activity related pain (paper 3). Participating in social situations and being able to fulfil societal roles seems to be an important incentive to endure pain (Borell et al. 2006).

5. CLINICAL IMPLICATIONS

Patient education and information are considered as significant elements in the treatment of chronic musculoskeletal pain (Henrotin et al. 2006). The European guidelines for prevention of low back pain recommend information on beliefs (Henrotin, Cedraschi, Duplan, Bazin, & Duquesnoy 2006). The main implication for clinical practice, obtained from the results of this thesis, is to include patients' stories, experiences and thoughts, as elements in treatment programs. It is strongly advised to make room for patients' own perceptions in addition to the traditional information from health care personal. There is still potential in clinical practice to develop patient information based on such principles (Carnes & Underwood 2008;McIntoshA & Shaw C 2003).

Questionnaires are frequently used for diagnostic and treatment purposes, and the Tampa Scale of Kinesiophobia has earned increasing recognition also in Norway (Damsgard, Fors, Anke, & Roe 2007;Haugen, Grovle, Keller, & Grotle 2008). However, one should bear in mind that some of the phenomena measured in questionnaires, as fear of movement/(re)injury, are theoretical constructs. Hence,

the Tampa Scale of Kinesiophobia may be used to asses the level of fear of movement/(re)injury, and based on the scoring a more individualized discussion with the patient could be carried out. For example, if fear of movement/(re)injury is not a problem to the patient, there is no need to address this issue. We would also advocate the use of PSOCQ. Assessing the patients' stage of readiness to adopt a self-management approach to pain could provide a useful discussion between patients and health care professionals about the treatment approach. These suggestions call for a more individualized diagnostic and treatment approach. Questions to be considered are: How does the patient describe and explain activity-related pain? How has the patient figured out how to manage this sort of pain? What are the patient's pain-related fears about? Is the patient ready for self management of pain, or does he or she need more medical support?

It appears that many of the patients in the present study have the resources to manage well despite some discomfort. It is important for health care professionals to understand and acknowledge the individual patients' pathway, and help the individual to continue in the right direction. It is also important to carry out a thorough examination of the patient in order to rule out or confirm biomechanical or pathophysiological reasons for pain, if possible. Having an explanation of the pain, even if there is "nothing to see" may contribute to the patient's understanding of the problem and provide him/her with some tools to manage the pain. It may be a good idea to tell him/her that the lack of objective proof of illness does not mean that his/her narrative is not taken seriously. Alternative explanations should be discussed and the patient's own understanding included.

6. CONCLUSIONS AND FUTURE PERSPECTIVES

The combination of qualitative and quantitative data has elucidated different aspects of activity related pain and pain related fear of movement/(re)injury. We have explored the associations of these phenomena, as well as the contextual perspectives and person-based understanding. Thus, we conclude that in this study

combining quantitative and qualitative research has been fruitful. Based on the mixed methods approach we conclude that:

- Increased pain during activity was reported by a majority of the participants, and was associated with high levels of fear of movement/(re)injury, large pain distribution and lower sense of self efficacy.
- Fear of movement/(re)injury was associated with increased pain during activity, also in individuals with non-elevated level of psychological distress. Individuals who were more ready to take a self management approach to pain presented with lower levels of pain during activity, less fear of movement/(re)injury, less psychological distress and higher level of self efficacy than individuals who were less ready to self management of pain.
- The Tampa Scale of Kinesiophobia seems well suited to assess fear of movement/(re)injury in patients with low back and more wide spread pain.
- Activity related pain and pain related fear had a contextual meaning as it was perceived differently in different situations. Uncertainty about the meaning of pain did not stop the participants from staying active, and incentives to stay active were the experience of activity as healthy and as key to participating in social life. This required calculating and planning, which became an integral part of everyday living.
- The Pain Stages of Change Questionnaire could be used to visually and by cluster analysis classify subjects with chronic pain into specific profiles of readiness to adopt a self management approach to pain. However, the process of visual classification was sometimes difficult.

Based on the conclusions in this study, further research on activity related pain is suggested. There are still ambiguities about the role of activity related pain in pain disability, and the relationship between activity related pain, level of physical activity, pain disability and psychosocial factors merits further research. It is also suggested to explore patients' perspectives for a more comprehensive understanding of experiences of pain and fear.

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Paper 1

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ORIGINAL REPORT

THE TAMPA SCALE OF KINESIOPHOBIA: A RASCH ANALYSIS OF ITS PROPERTIES IN SUBJECTS WITH LOW BACK AND MORE WIDESPREAD PAIN

Elin Damsgård, RN, Cand.San[1], Terese Fors, MD[1], Audny Anke, MD, PhD[1] and Cecilie Røe, MD, PhD[2]

From the [1]Department of Physical Medicine and Rehabilitation, University Hospital of Northern Norway and University of Tromsø and [2]Department of Physical Medicine and Rehabilitation, Ullevål University Hospital, Norway

Objective: **The aim of this study was to investigate the psychometric properties of the Norwegian version of the Tampa Scale of Kinesiophobia in patients with low back pain and in patients with more widespread pain distribution including low back pain.**

Subjects: **A total of 120 subjects, 48 with isolated low back pain and 72 with more widespread pain distribution were included.**

Design and Methods: **The Norwegian translation of the Tampa Scale of Kinesiophobia, Hopkins Symptom Check List 25 question version and Fear Avoidance Behaviour Questionnaire were completed. The properties of the Norwegian translation of the Tampa Scale of Kinesiophobia were explored by a Rasch analysis.**

Results: **The Tampa Scale of Kinesiophobia fitted the Rasch model and passed the independent *t*-test for a unidimensional scale. The response categories for some of the items needed to be collapsed from 4 to 3 levels. Only the item "It's not really safe for a person with a condition like mine to be physically active" was significantly different in men and women.**

Conclusion: **The Norwegian translation of Tampa Scale of Kinesiophobia seems to reflect a unidimensional construct of kinesiophobia. The scale seemed to be quite robust across age and gender, and the response patterns to the items were similar in patients with low back pain and widespread pain distribution including low back pain.**

Key words: Tampa scale, kinesiophobia, pain, Rasch analysis, fear avoidance.

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Correspondence address: Cecilie Røe, Department of Physical Medicine and Rehabilitation, Ulleval University Hospital, NO-0407 Oslo, Norway. E-mail: eller@medisin.uio.no

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INTRODUCTION

The purpose of the present study was to assess the psychometric properties of the Tampa Scale of Kinesiophobia (TSK). The TSK questionnaire aims to assess fear of movement in patients with chronic musculoskeletal pain (1). Fear of movement is believed to be a significant factor in the development of chronic pain, and in some studies, kinesiophobia as evaluated by the TSK, has been shown to help predict pain disability (2–5).

Fear of movement may be regarded as one phenomenon within a framework of a Fear- Avoidance Theory (6, 7). The essence is that the experience of pain leads to fear, which leads to avoidance behaviour, such as avoiding movements connected with physical activity during daily life, exercise, or work activities. Central constructs in these theories are pain-related fear, fear of movement/fear of re-injury and fear-avoidance beliefs (1, 6–8).

Pain-related fear is based on an understanding of pain as a sign of harmful bodily processes, and makes any pain connected with physical activity interpretable as potentially dangerous. This interpretation leads to attention being focused on the source of the threat; in this case bodily sensations are interpreted as signs of serious health problems (9). Depending on the person's individual history, personality and genetics, they will develop a fear, and therefore avoidance, of movement and physical activity (2, 7). The fear of physical activity and the subsequent avoidance behaviour has also been described as a phobic fear of movement, kinesiophobia, connected with chronic pain behaviour (1). Kinesiophobia refers to "an irrational and debilitating fear of physical movement resulting from a feeling of vulnerability to painful injury or re-injury" (1). The phenomenon has later also been described as fear of movement/re-injury, and refers to an idea of having a vulnerable, easily harmed body, and that movement may cause re-injury (2).

Two of the main instruments developed based on these theories are the Fear Avoidance Beliefs Questionnaire (FABQ) (7, 10) and the TSK, originally a 17-item instrument containing 4 reversed questions (1). The FABQ focuses on the relationship between pain and physical activity, and pain and work activity. The questionnaire has been found to be a valid instrument for the assessment of fear avoidance beliefs across patients with low back pain (LBP) (7) and has been validated in Norwegian. The TSK focuses on beliefs of pain and exercise, and it is not related to work situations. It has been translated into Dutch and Swedish (2, 11). Furthermore, it has been found to be a valid and reliable instrument for estimating the fear of movement and re-injury in patients with LBP as well as in patients diagnosed as having fibromyalgia (5, 12, 13). It was recently translated into Norwegian by Julsrud Haugen and Grøvle (Sarpsborg

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Hospital, Norwegian translation of TSK, unpublished), and not yet validated. Nor, to our knowledge, has it been tested on patient groups with LBP in association with more widespread pain, like the one presented in the present study. Most of the patients presenting at the clinic have more widespread pain, typically neck and shoulder pain in addition to LBP. It would thus be of interest to investigate the level of fear of movement/re-injury in this patient group too.

Studies of the TSK have revealed various factor structures, from 1 to 5 factors (2, 5, 11, 12, 14). However, agreement has been reached regarding a 13-item version with exclusion of the reversed items (12), and has been used in the present study. A 4-factor structure, including factors labelled harm, fear of re-injury, importance of exercise, and activity avoidance has been used in patients with LBP (12). However, in other studies, several other factor structures have also been identified in patients with LBP, with respect both to the number of factors and to the items included in the factors (5, 11, 12). The unstable factor structure may be caused by differences between populations, as well as translation bias and cultural differences. The factor structure presented in these studies was based both on the principal component and related parametric analysis, and on subsequent confirmatory analysis. As the TSK represents an ordinal, but not necessarily an interval, scale, and the variance in different groups with respect to fear of movement/re-injury may vary, other approaches for investigating the properties of this scale may be needed. More recently, models based on the Rasch measurement model (15), have been developed further for application to the multiple response categories of Andrich (16). This approach will help investigate the underlying constructs of measurements. Ideally a measurement should reflect a single construct, often termed unidimensional (17). The Rasch analysis also allows investigation of item and person responses and ordering the response categories (18). The ordering of the items in this context reflects the degree to which the items reflect the fear of movement trait. This type of evaluation of the items in measurements of fear avoidance and fear of movement has not been undertaken previously. However, the previous factor structure might indicate that the questions about exercise reflected more of the fear of movement/re-injury trait than the other questions. Hence, the other questions are often grouped in a somatic factor according to previous factor structures (5). As age and gender have been shown to influence measurements reflecting psychological traits and quality of life (19), these factors should be taken into consideration when evaluating a measurement. In addition, gender differences in pain are well known (20) and have been assumed to influence the item responses in TSK. The reported differences in factor structure in patients with LBP and fibromyalgia could indicate variance across subjects with LBP and more generalized pain (14).

Hence, the aims of the present study were to use Rasch analysis to examine:

- the fit of the items and their response categories
- the fit and distribution of the subjects
- whether the pain distribution, age, or gender influenced the response pattern to TSK
- whether the translated version of TSK reflects an unidimensional construct.

MATERIAL AND METHODS

Subjects

Patients were recruited from subjects referred to The University Hospital of Northern Norway, Department of Physical Medicine and Rehabilitation in the period October 2005 to March 2006 inclusive. An invitation to participate in the study, information about the study and a consent form, along with the questionnaires were posted to the patients a few weeks before they entered the department. A total of 265 patients met the inclusion criteria and were invited to participate. The patients were asked to fill in the questionnaires and bring them with them to their first consultation. A total of 120 patients gave informed consent and had completed the questionnaires satisfactorily. All patients with pain including the low back, and complete registrations in TSK, FABQ and Hopkins Symptoms Checklist (HSCL-25), were included. The study was approved by the Norwegian Regional Committee for Medical Research Ethics.

Procedure

The distribution of pain during the last 2 weeks was marked in the Norwegian form of the McGill Pain Questionnaire (21). According to the pain drawings and pain ratings last week on a numeric scale, the patients were grouped as subjects with LBP (pain localized to the low back, and low back and leg), and as subjects with LBP in association with more widespread pain (WP) (i.e. low back/leg pain and pain in additional body areas). Patients with pain drawings covering more than one area were classified as WP if their scores on the numeric scale was higher than "2" in both the back/leg and the other areas. The questionnaires also comprised information about socio-demographic data, work-load and work satisfaction, physical activity, and previous treatment.

The Tampa scale of kinesiophobia (TSK). A 13-item questionnaire aimed at the assessment of fear of movement/re-injury. Each item is provided with a 4-points Likert scale with scoring alternatives ranging from "strongly disagree" [0] to "strongly agree" [4] (12). This gives a possible total raw score range from 0 to 52. With their permission, we used a version translated by Julsrud Haugen and Grøvle. This translation was based on a bilingual forward and backward translation followed by a consensus conference as recommended by Beaton et al. (22).

The fear avoidance beliefs questionnaire (FABQ). The FABQ consists of 2 scales: 5 items focus on fear avoidance beliefs of physical activity and 11 items focus on fear avoidance beliefs of work. The scoring options were on a 6-level Likert scale ranging from "totally disagree" [0] to "totally agree" [6]. Four items are used for the FABQ "physical activity" using a raw score from 0–24.

Hopkins symptoms check list (HSCL-25). The HSCL-25 (23), Norwegian version (24), contains 25 questions comprising the dimensions of somatization (items 3, 8, 11, 14, 15, 16 and 24). It is scored on a 4-level Likert scale, ranging from not at all [0] to very much [4]. This gives a possible total raw score range for HSCL-25 from 25 to 100 and for the dimension of somatization from 7 to 28.

Pain. Pain intensity during rest and activity were reported on a numeric scale, ranging from 0 (no pain) to 10 (worst imaginable pain). Pain was reported for low back, leg, neck/shoulder/arm, both during rest and activity.

Statistics

Gender differences between the LBP and WP groups were investigated by Fischer's exact test. The group differences with respect to TSK and HSCL-25 scores were examined by the *t*-test for independent samples.

Rasch analysis. Internal construct validity of the TSK was explored by a Rasch analysis. This model assumes that the probability of a patient affirming a trait, for example fear of movement/re-injury, in an item of a questionnaire depends on the patient's level of that trait (θ) and the level of fear of movement/re-injury expressed by the item (b). In a model where there are several response categories the model is expressed as (16):

$$\ln (P_{ni}/1\text{-}P_{ni}) = \theta_n\text{-}b_i\text{-}\tau_i$$

where P_{ni} is the probability that a person n will affirm the item, θ_n is the person's level of the trait, and b_i is the level of the trait expressed by the item, and τ_i represents the 0.5 probability point (threshold) between adjacent response categories for that item. The responses are distributed along a logit scale. The partial credit variant was applied as this model is valid without assumption of equidistance between thresholds across items (25).

The overall summary fit was evaluated by the χ^2 item trait interaction statistics. This represents the added χ^2values for the individual scale items, and the probability value (*p*) is determined according to the summated degrees of freedom (25). A non-significant probability value indicates no substantial deviation from the model, and a hierarchical ordering of the scale items across all levels of the underlying trait. Two subsets of items were created, representing the items with the most positive and most negative residuals according to a Principal Component Analysis. Person estimates for each of the 2 subsets were calculated, and independent *t*-tests comparing the 2 estimates in each person were performed. Number of *t*-tests with *p*-values below 0.05 and the corresponding confidence interval (CI) were reported.

The individual persons and items were reported as mean and standard deviation (SD), and a mean of 0 and SD of 1 represent optimal fit. The fit of the items was statistically evaluated by residuals and χ^2 statistics. Item residuals ± 2.5 and a non-significant χ^2 probability value were considered to indicate adequate fit to the Rasch model (26). The person separation index is reported, providing an indication of the power of the measure to discriminate among persons with different levels of the trait. A value above 0.8 was deemed to differentiate across at least 3 patient groups.

Differential item function (DIF) was based on analysis of variance for each item, comparing scores across each level of age, gender and pain distribution (27). DIF for age was analysed, grouping the subjects below and above the median age of 42 years. Both significant main effects of age, gender and pain distribution (uniform DIF), and interaction (non-uniform DIF) between age, gender and pain distribution and subgroups of the patients (class interval) were evaluated. F ratio (F) for the group difference and probability (*p*) were given. A significance level of 0.05 was adopted, adjusted for testing of 13 items for the fit, and 13 items and 2 groups for the DIF analysis (28). The Rasch analysis was performed in RUMM 2020 (RUMM laboratory, Perth, Australia). Other analysis was performed by SPSS for windows version 13.0.

Table I. *Self-reported pain on a numeric scale, ranging from 0 = no pain to 10 = worst imaginable pain, during rest and activity*

Activity/rest	Low back pain (*n* = 48) Median (range)	Widespread pain (*n* = 72) Median (range)
Low back pain		
during rest	5 (0–10)	2 (1–10)
during activity	7 (2–10)	3 (0–10)
Leg pain		
during rest	3 (0–10)	2 (1–10)
during activity	5 (0–10)	6 (0–10)
Neck/shoulder/arm pain		
during rest	0 (0–8)	2 (2–10)
during activity	0 (0–9)	3 (2–10)

RESULTS

A total of 120 patients participated, 48 with LBP and 72 with WP. The mean age was 42 (SD 10) years in both groups. In the LBP group, 42% were females, 58% males. In the WP group, the gender distribution was 58% female and 42% males ($p = 0.09$). Slightly more than one-third of the subjects were single in both groups. Pain characteristics of these groups are given in Table I. FABQ scores for the "Physical activity" – dimension of the questionnaire were 13 (SD 6) for LBP and 14 (SD 5) for WP patients ($p = 0.10$). The HSCL-25 scores for somatization were 14 (SD 4) and 17 (SD 4) for LBP and WP, respectively ($p = 0.92$). The TSK scores were 31 (SD 6), and 31 (SD 7), for the LBP and WP groups, respectively ($p = 0.17$).

The fit of the items and their thresholds

In general, the items were found to fit the model (mean item fit = 0.26 (SD 0.86). None of the items were outside the range of fit residual value of ± 2.5 (Table II). Positive locations of items 4 and 7–13, indicate that these items express above average of the

Table II. *Fit of the items of the Tampa Scale of Kinesiophobia (TSK) to the Rasch model*

Item	Location	SE	Residual	χ^2	Probability
TSK 1. People aren't taking my medical condition seriously enough	–0.52	0.12	1.36	4.47	0.11
TSK 2. My body is telling me I have something dangerously wrong	–1.25	0.13	1.13	1.00	0.61
TSK 3. My accident has put my body at risk for the rest of my life	–0.75	0.12	0.22	0.26	0.88
TSK 4. I am afraid I might injure myself accidentally	0.16	0.10	0.02	4.96	0.08
TSK 5. If I were to try to overcome it, my pain would increase	–0.24	0.11	0.52	0.70	0.71
TSK 6. Simply being careful that I do not make any unnecessary movements is the safest thing I can do to prevent my pain from worsening	–0.59	0.11	–0.37	0.44	0.80
TSK 7. I wouldn't have this much pain if there weren't something potentially dangerous going on in my body	0.67	0.12	0.67	0.99	0.61
TSK 8. Pain always means I have injured my body	0.28	0.11	–0.35	0.16	0.92
TSK 9. Pain lets me know when to stop exercising so that I don't injure myself	–1.03	0.12	1.17	5.91	0.05
TSK 10. It's not really safe for a person with a condition like mine to be physically active	1.28	0.13	–1.54	5.17	0.08
TSK 11. I'm afraid that I might injure myself if I exercise	1.01	0.12	–0.17	0.85	0.66
TSK 12. I can't do all the things normal people do because it's too easy for me to get injured	0.39	0.11	–0.52	2.15	0.34
TSK 13. No-one should have to exercise when he/she is in pain	0.65	0.12	1.28	0.21	0.90

SE: standard error.

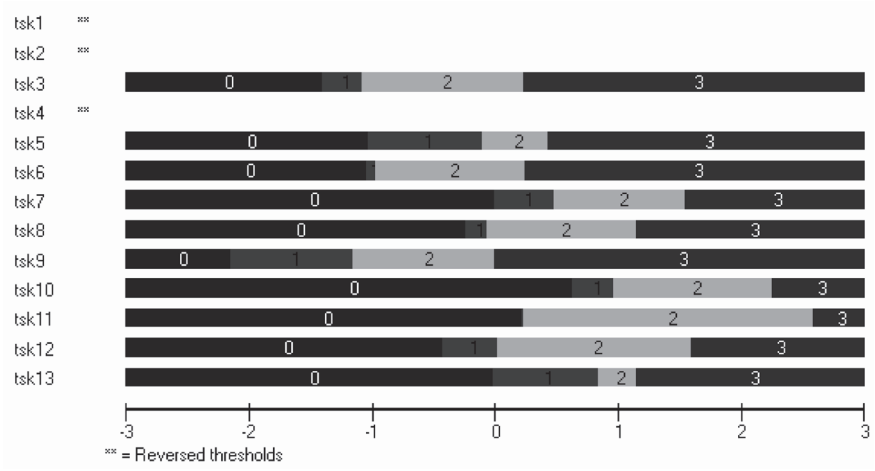

Fig 1. Threshold map showing the ordering of the scale levels of items (TSK 1–13) in the Tampa scale. The x-axis representing the logits, and the Likert score levels from 0 to 3 given for each item. Item TSK 1, 2 and 4 not visualized according to reversed threshold. For these items the probability threshold was lower for Likert score 2 compared with 1. The questions that the TSK items refer to are shown in Table II.

trait captured by the TSK total score. However, items 1, 2 and 4 had reversed thresholds (Fig. 1). The probability threshold of these items was lower for Likert score 2 compared with 1. Hence, these items were re-scored according to a pattern of 0, 1, 1, 3. Meaning that response at level 1 and 2 are treated as the same category.

Fit of the subjects

The mean person fit was –0.17 (SD 1.15). The Person Separation Reliability was 0.87. Only 2 subjects were extremes and scored no fear of movement/re-injury at all. Both were males above 42 years of age with LBP.

Targeting

The items had a logit distributions from –3.2 to 3.2 (Fig. 2). The mean location for the persons was –0.208 (SD 1.12), indicating that the subjects have a slightly lower level of fear of movement/(re)-injury than the average scale items (expected to be 0 logits).

The items including physical activity and exercise were located in the upper hierarchy among the items. The threshold from some agreement to strongly agree for item 11 "I'm afraid that I might injure myself if I exercise" reflects the highest level of fear of movement/(re)injury, (Fig. 2). Hence, this item was difficult to endorse for almost all patients with LBP. The thresholds between strongly disagree and some disagreement for item 2: "My body is telling me I have something dangerously wrong" reflect the lowest level of fear of movement/re-injury. There is a gap in the upper level of the scale for the subjects, and none of the items expressed the absolute minimal or maximal (of the) trait of fear of movement/re-injury. However, the items and subjects are well distributed along the logit distribution with item and subject mean values close to each other. Hence, the targeting of the scale is quite good.

Invariance across age, gender and pain distribution

A uniform DIF of the item responses according to age, gender or pain distribution was not found, except for item 10, which varied according to gender. Assuming equal underlying levels of fear of movement/re-injury, men were more likely than women to think that it was not safe to be physically active with a condition like theirs (F = 12, $p = 0.0006$) (Fig. 3). The level mean for this item was 0.91 for men and 0.32 for women, and the location 0.81 (SE 0.17) for men and 2.64 (SE 0.23)

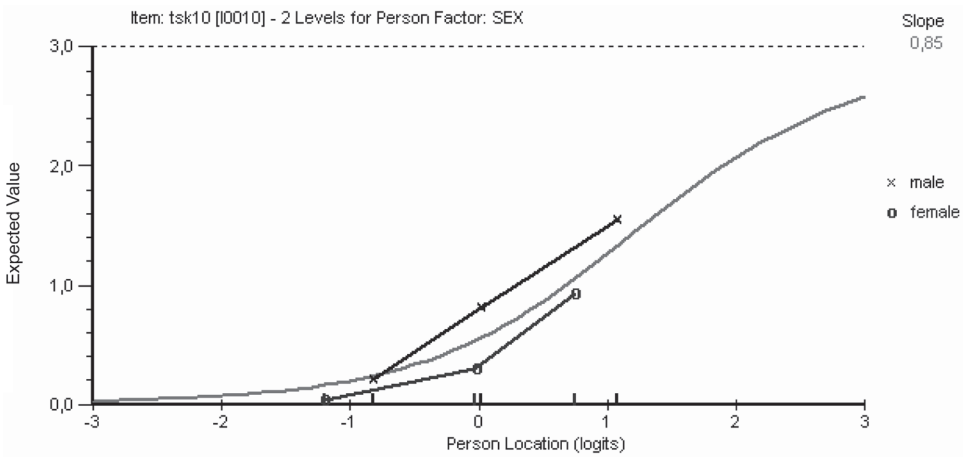

Fig. 2. Differential item functioning across gender for item 10: "It's not really safe for a person with a condition like mine to be physically active".

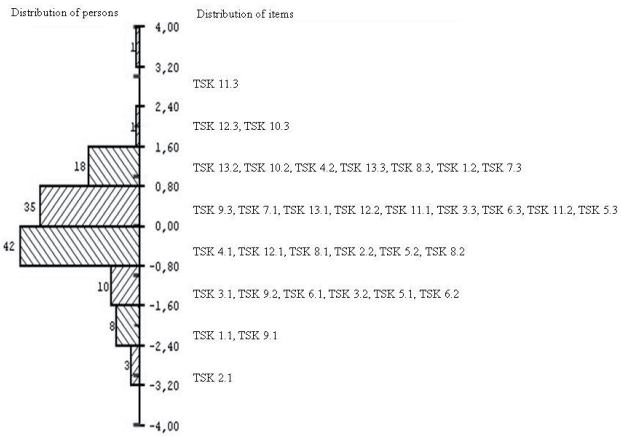

Fig. 3. Distribution of the threshold for the items and the subjects (n = 118, 2 extreme subjects excluded) along Rasch calibrated metric scale of the attribute being measured as kinesiophobia. The right-hand panel shows the location of the items and their thresholds are indicated by the decimal. The left-hand panel shows the distribution of persons. Item 2 in Tampa Scale of Kinesiophobia (TSK) (TSK 2) capturing least and item 11 (TSK 11) capturing most of the trait of fear of movement/re-injury. The questions which the TSK items refer to are shown in Table II.

for women (Fig. 4). Non-uniform DIF was not found for any item or person characteristics.

Construct unidimensionality

After re-scoring items 1, 2 and 4 as described above, the overall fit of the TSK to the Rasch model was evaluated. The χ^2 item trait interaction statistics was 27.27, $p = 0.40$ and indicated a fit to the Rasch model. The overall fit indicates a unidimensional underlying construct of fear of movement/re-injury. However,

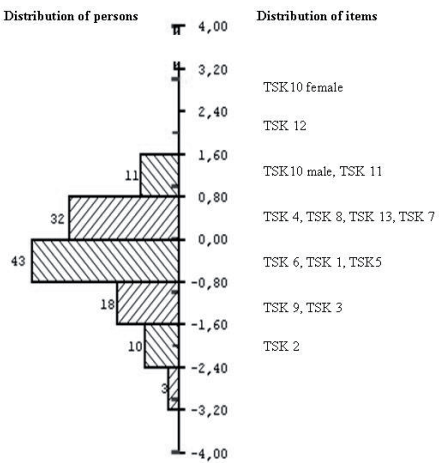

Fig. 4. Distribution of the items and the subjects (n = 118, 2 extreme subjects excluded) along the Rasch calibrated metric scale of the attribute being measured as fear of movement/re-injury. The right-hand panel shows the location of the items. The left-hand panel shows the distribution of persons. The location of item 10 is given separately for men and women. The questions to which the Tampa Scale of Kinesiophobia (TSK) items refer are shown in Table II.

the evaluation of unidimensionality was also based on analysis of the residual patterns of the Principal Component Analysis. Two subsets of items (2, 3, 5, 7 and 8) and (6, 10, 11, 12, 13) represented the items with the most positive and most negative residuals respectively. Person estimates for these 2-item sets were calculated and compared by independent t-tests. Although 9.1% of the tests were outside the range of ±1.96, the CI for this probability was 0.05 to 0.13 according to the binominal test, hence deemed as the acceptable border for unidimensionality of the scale as a whole.

DISCUSSION

The present study clearly indicates that the Norwegian version of TSK represents a unidimensional construct capturing fear of movement/re-injury.

Validating a questionnaire means testing to what degree the questionnaire measures what it is meant to measure. In addition to the theoretical framework on which TSK is based (1), several aspects of the validity of this scale have been explored earlier (14). The scale has been tested and found reliable and its predictive value has been assessed (2). However, concern has been related to the construct validity of this instrument, that is; the underlying attribute(s) that is (are) captured (29). The construct validity of the TSK has been explored through factor analysis as well as through the known groups method (9, 11). Studies have revealed a factor structure from 1 to 5 factors (2, 5, 11, 12, 14). Also the loading of items in different factors varies (30). These results may indicate that the TSK does not represent a unidimensional underlying construct. However, methodological issues related to the TSK do not meet the strict requirements of a linear interval scale on which factor analysis is based (31). Hence, in the present study, a Rasch approach exploring the construct and properties of the TSK was used.

First of all, the Rasch approach offers a linear transformation of the ordinal raw score of the TSK (15, 16). Secondly, several other methodological aspects of the scale related to the fitting of single items, ordering of the response categories and the differential function across subgroups of subjects or patients can be evaluated. There is an ongoing discussion about the choice between the rating scale and the partial credit model in Rasch measurement. The rating scale model specifies that a set of items share the same rating scale structure, whereas the partial credit model specifies that each item has its own rating scale structure (32). As the TSK did not meet the requirements of the same rating scale structure across items, we chose the partial credit model.

The present translation of the TSK shows a reasonable fit to the Rasch model, and seems to represent a unidimensional underlying construct. We suggest that Rasch analysis represents a more valid analysis strategy for this type of measurements (33), and the discrepancy between the studies indicating multidimensionality is related to the factor analysis method, and not a translation bias. Our results agree with the conclusions reached by Houben et al. (34), even though this study did not

apply a Rasch approach. Furthermore, it is the use of TSK without factorizing that has proved to predict disability (2, 35), and the internal consistency of all 13 items in the TSK was quite high.

The items 1:"People aren't taking my medical condition seriously enough", item 2:"My body is telling me I have something dangerously wrong" and item 4: "I am afraid I might injure myself accidentally", had a problem with the threshold for scoring some disagreement.

This problem was solved by combining the responses "some disagreement" and "some agreement". None of the items misfitted the model, whereas 2 male subjects did, scoring no fear of movement/re-injury at all. These subjects also reported no fear of avoidance on the FABQ physical dimension, supporting the relationship between fear of movement/re-injury and fear avoidance (2).

The TSK also seems to be well targeted. The scale also showed acceptable invariance, showing that the items responded consistently across age, gender and pain distribution. The number of subjects in the LBP group was only 48. However, based on the calculations of Elasoff (36), differences of 0.1 logits could be detected in DIF analysis in groups down to 25 subjects, given a power of 80%. It was only in the responses to the question "It's not really safe for a person with a condition like mine to be physically active" that we observed a uniform difference between men and women. This item was the most difficult to endorse for women, whereas item 12 "I can't do all the things normal people do because it's too easy for me to get injured" was most difficult for the men, and item 10 the second most difficult to endorse. Thus, item 10 is in the upper hierarchy of the items for both sexes. The different order of item 10 between men and women could reflect gender differences regarding opinions on "things normal people do." Hence, across gender fear of injury was reflected to a larger extent in the questions related to physical activity and exercise, than in the questions related to more general thoughts about what is going wrong in the body and provoking pain.

The invariance of a scale is important both because it confirms that the scale is measuring a consistent underlying construct, and because it can be applied to different patient populations. We did, however, find a uniform DIF for the question: "It's not really safe for a person with a condition like mine to be physically active". This result could indicate that the estimates should be performed separately for men and women, but we would recommend that this difference should be investigated in additional studies before strong recommendations are given. Furthermore, it is a matter of discussion of how different the present 2 patient groups really are, considering that both groups have LBP, and whether DIF might be found to a larger extent in patient populations with more differences. In agreement with the present results, previous studies using factor analysis have found acceptable internal consistency of TSK subjects both with acute and chronic LBP and with more widespread pain (12, 37). Furthermore, in a modified TSK version, a unidimensional construct is documented in subjects without pain (34), giving support to the results of invariance in the present study. However, the level of fear of movement/re-injury was similar in LBP and WP in the present study, and no DIF were found. Hence, it may be appropriate to use Rasch analysis applied to TSK in diagnostic groups with more differences than in the present study.

The Rasch analysis providing evidence for the measurement of a unidimensional construct does not provide any information about the nature of this construct. Previous studies have suggested different constructs measured by the TSK. "Somatic focus" (12), "Activity Avoidance factor" and "Fear of harm" (38) are constructs suggested to be reflected by the TSK. Burwinkle et al. (14) argues that the items in the TSK appear to reflect beliefs that do not necessarily relate to fear of movement, but assess a general sense of vulnerability.

Approximately half of the invited patients volunteered to participate in the present study. The inclusion based on only written information may give rise to a lower attendance rate and possibly a selection of subjects with higher level of education. However, the regional ethics committee had suggested this procedure to be preferable to the persuasion, which may be a problem when the patients are invited in the clinical situation. The HSCL-25 scores on the somatization dimension and the FABQ scores indicated that this group had higher levels of somatization and fear avoidance than the general population, which has been shown to be predictive to persistence of pain. With respect to gender and age distribution, there were no significant differences between participants and non-participants.

The response to TSK was explored in a population with dominating LBP or more WP pain. Leg pain in patients with LBP is assumed to have its origin from the back, either as a sign of nerve root affection or referred pain from the back muscles, and does not represent a more widespread pain pattern. A tendency was found towards there being more women in the WP group, which is in accordance with the gender distribution of more generalized pain in the Norwegian population (39). Otherwise the groups showed a similar level of fear of movement/re-injury and fear avoidance to that evaluated by the TSK and the FABQ scores. As the 2 patient groups turned out to be fairly similar regarding level of fear of movement/re-injury, and the LBP group was rather small, further analysis of invariance of the TSK may be warranted.

In conclusion, the Norwegian translation of TSK seems to reflect a unidimensional construct of fear of movement/re-injury. The internal consistency and criterion validity was acceptable, and the scale seemed to be quite robust across age and gender, and also for patients with LBP and WP.

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Paper 2

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Activity related pain in patients with chronic musculoskeletal disorders

Elin Damsgård, R.N., Cand. San[1], Gyrd Thrane, PT, Cand. San[2], Audny Anke MD, PhD [1], Terese Fors, MD[1], Cecilie Røe, MD, PhD[3,4].

[1]Institute of Clinical Medicine, University of Tromsø and
Dep of Physical Medicine and Rehabilitation, University Hospital of Northern Norway.
[2]Faculty of Health Sciences, Tromsø University College.
[3]Dep of Physical Medicine and Rehabilitation, Ullevål University Hospital, Oslo, Norway.
[4] Faculty of Medicine, University of Oslo, Norway

Corresponding author: Elin Damsgård, [1]Institute of Clinical Medicine, University of Tromsø and Dep of Physical Medicine and Rehabilitation, University Hospital of Northern Norway.
E- Mail: Elin.Damsgard@fagmed.uit.no

Abstract

Purpose. Activity related pain may be a barrier to rehabilitation in patients with chronic musculoskeletal disorders. This study investigated patients' reports of increased pain during activity, and the association between such pain and psychological factors and pain variables.

Method. Questionnaires from 232 adults with chronic musculoskeletal pain measured pain intensity, spread of pain and pain duration. Pain during activity was assessed both on a 11 point Numeric Rating Scale (NRS), and operationalized as a dichotomous measure, where responders defined if they experienced pain during general activity and exercise. Psychological factors were measured by the Hopkins Symptom Check List 25, the Tampa Scale for Kinesiophobia and a subscale of the Arthritis Self – Efficacy Scale. Multiple and logistic regression was used to analyse associations between increased pain during activity and associated variables.

Results. Increased pain during activity was reported by 69 % of participants. Fear of movement was a significant factor for reporting increased pain during activity, both general activity and exercise, also in a subsample with low psychological distress. Other significant factors were spread of pain and a low sense of self efficacy.

Conclusion. Patients with high fear of movement, large spread of pain and low self efficacy were more likely to report increased pain during activity even in the absence of psychological distress.

Introduction

One of the most common treatment offers for musculoskeletal pain is exercise [1] and there is agreement that physical activity is important for the rehabilitation of patients with chronic musculoskeletal disorders [2;3]. However, according to clinical observations many patients with musculoskeletal pain report increased pain when exercising, or even in activities of daily life. In a study by Brox et al [4] pain during activity in a population of patients with low back pain (LBP) was reported significantly higher in subjects with chronic pain compared to subacute and healthy controls. Relations between physical exercise and musculoskeletal pain also seems to be affected by the mode of exercise/sport, and of factors like stress and work-related physical loading [5]. Increased pain after exercise is a well known phenomenon also among healthy people, known as DOMS (Delayed Onset Muscle Soreness), due to physiological reactions in the muscles [6]. However, we lack information about the prevalence of this pain problem in patients with chronic musculoskeletal disorders, as well as the characteristics of patients experiencing such pain.

The mechanisms behind increased pain during activity in patients with chronic musculoskeletal pain still remain, at least partly, unknown. Pain is a complex experience, and the perception of pain during exercise and physical activity in general may be related to several factors. The growing body of research in this area have revealed the impact of psychological and behavioural factors in chronic pain and disability [7-9]. Fear of movement / (re)-injury is one phenomenon within a theory of fear avoidance, and has in some studies been a predictor of pain-related disability and chronic pain [10;11]. The

essence is that pain is interpreted as a sign of danger, and consequently physical activity is avoided. However, the association between pain-related fear avoidance and functional, as well as exercise, capacity has not proven consistent [12-15]. While it is possible that fear of movement predicts pain-related disability, there is some evidence that a person's self-efficacy may mediate disability levels in patients with chronic musculoskeletal pain [16;17]. Self-efficacy refers to a person's beliefs about his or her own ability to manage situations and perform tasks [18]. Studies have shown that the level of self-efficacy on function and pain management is an important factor in pain disability and management, but the contribution of self-efficacy is not consistent [19;20].

Another important factor associated with chronic pain is psychological distress. It is known that psychological distress is elevated in individuals with chronic musculoskeletal disorders [21;22], but it is unclear how it associates with increased pain during activity in these populations. In the previously mentioned study by Brox JI et al [4], the level of psychological distress follows a stepwise increase from low level in healthy controls, to increasing levels in patients with subacute LBP and chronic LBP. Psychological distress seems to be conceptually related to fear of movement, as questionnaires assessing both these phenomena seem to reflect awareness of sensations from the body. It would thus be interesting to explore if fear of movement / (re)-injury is associated with activity-related pain also in patients with non-elevated levels of psychological distress. The result of this exploration could shed light on the eventual similarity or distinction between pain-related fear and general anxiety and somatisation in individuals with activity-related muscle pain.

The role of pain and fear of movement / (re)-injury, self-efficacy and psychological distress in predicting activity limitations and disability is an ongoing discussion. So far, research indicates that pain variables and psychological factors are strongly interrelated though the direction of relationship unrevealed [23-25]. However, less is known about the role of these factors in individuals' perception of increased pain during activity. Knowledge in this area could be useful for educational as well as exercise programs in rehabilitation of patients with chronic musculoskeletal disorders.

Hence, the aim of this study was a) to investigate the occurrence of increased pain during activity in patients with chronic muscular pain, and b) to explore the association between fear of movement, psychological distress, self-efficacy and pain related to general activity and exercise.

Methods

Inclusion

Data were from questionnaires distributed to outpatients at the University Hospital of Northern Norway, Department of Physical Medicine and Rehabilitation, Neck and Back unit in the period from October 2005 through October 2006. The unit receives patients referred from primary health-care with various musculoskeletal complaints (ICD 10 diagnosis M00-M99). In this period 549 eligible patients were referred. Patients completed the questionnaires including information about age, gender and education. The informed consent form was signed prior to the consultation. Inclusion criteria were first

time visit, understanding and speaking Norwegian language and age between 18 and 67 years. Patients with suspected malignant diseases stated in the referrals were excluded. Two hundred and sixty three subjects (48 %) met the inclusion criteria and consented to participate. Thirty one responders were later excluded due to incomplete questionnaires (two or more items missing in scales/ subscales), leaving data from 232 patients (42 %), mean age 42 (SD 10.0) years, to be entered into analysis.

The study was approved by the Regional ethical committee for medical research in Northern Norway.

Instruments

Pain intensity

Pain intensity was measured by a numeric rating scale (NRS) [26]. Patients were asked to mark on scales from 0 (no pain) to 10 (worst pain imaginable) how much average pain they had experienced during the latest week "at rest" and "during activity". We asked for one score on each scale, without distinguishing different activities, in order to limit the response alternatives and thus make it easier for patients to score. In this way we hoped to get more accurate data and minimize recall bias [27]. Assessment of average pain during one week is a reliable estimate for how patients recall their fluctuating pain [28] and is commonly used in clinical studies [29].

Increased pain during activity

Increased pain during activity was assessed in two ways. One was by subtracting each subject's score on the NRS for 'pain at rest' NRS from the score for 'pain during activity' [30]. The presence or absence of pain on activity was operationalized by self reports where the responders answered "yes" or "no" to the question whether they experienced increased pain during general activity or exercise, in case they currently exercised or used to exercise.

Spread of pain

Spread of pain on a continuum was assessed by pain drawings from the validated Norwegian form of the McGill Pain Questionnaire [31]. On the drawing of the front and back of the body a total of 100 squares cover the whole body surface. The respondents are asked to shade the squares covering a painful area. Spread of pain can be measured in different ways, for example by counting painful sites [32] or by calculating the percentage of body surface marked by the patient as painful [33]. By counting shaded squares we could get quite an accurate measure of the pain distribution.

Pain location

Based on the clinical examination as well as the pain drawings the participants' pain locations were categorized as: neck / shoulder / arm pain, low back / leg pain and multiple pain sites.

Physical activity

The level of physical activity was assessed by a subscale of The Saltin and Grimby Physical Activity Questionnaire reflecting levels of leisure time physical activity. The questionnaire is validated for middle aged men [34] and has been widely used in different health related studies [35;36]. The questionnaire is easy to fill in. It has four response options, and respondents are asked to mark the best fitting expression from 'totally disagree' to 'totally agree'. Only two respondents answered at level four, thus level 3 (high activity) and level 4 (very high activity) were collapsed for the analyses.

The Tampa scale of kinesiophobia (TSK)

TSK is a 13-item questionnaire aimed at assessing pain-related fear of movement / (re)-injury [8]. Each item is provided with a 4 points Likert scale with scoring alternatives ranging from 'strongly disagree' to 'strongly agree'. The scores for the 13 items are summed, which gives a possible range from 13 - 52. The Norwegian form of the TSK has been found a valid and reliable instrument, with an internal consistency of 0.81 (Chronbac's Alpha) and correlated to the Fear Avoidance Belief Questionnaire. A unidimensional underlying construct reflecting fear of movement/(re)-injury was found with Rasch Analyses [37-39].

Hopkins symptoms check list 25 (HSCL 25)

Psychological distress was assessed by the Norwegian form of Hopkins Symptom Check List, 25 questions version (HSCL 25) [40] the validated Norwegian version [41]. The questionnaire contains 25 questions comprising the dimensions of depression, anxiety and somatisation, and strong relationship between the dimensions have been confirmed

by Rasch analyses [42]. The items are scored on a 4 points Likert scale rating from ‘not at all’ to ‘very much’, summed and then divided by 25. The cut off score for HSCL is suggested to be 1.70, indicating psychological distress in subject with scores > 1.70 [41].

Arthritis self-efficacy scale (ASES) (the self-efficacy for pain subscale)

Self-efficacy was assessed by the subscale for pain in the Arthritis Self-Efficacy Scale, originally developed for patients with rheumatoid arthritis [43]. The instrument has been validated for a Swedish population [44] and a Norwegian version of the ASES self-efficacy for pain subscale has been used in several studies on back pain [4;19]. The scoring options for the self-efficacy for pain subscale were on a 6 level Likert scale ranging from ‘totally disagree’ (0) to ‘totally agree’ (6) with a possible raw score for each of the five questions from 0-6. The scores for the 5 items are summed and divided by 5, which gives a possible range from 0-6.

Data analyses

For statistical analyses, SPSS 15.0 was used. Data were first explored by descriptive statistics. In 20 % of the subjects, one item was missing in either HSCL 25, TSK or ASES. To preserve variance the missing items were substituted by the subjects mean score on subscales in the respective questionnaires [45]. Data on pain and psychological variables were normally distributed, and gender differences were explored with t-tests. Differences between different levels of physical activity and pain location areas were explored with one way ANOVA. In order to explore the occurrence and actual increase

of pain from rest to activity we subtracted each subject's score for 'Pain at rest' NRS from the score for 'pain during activity' NRS.

We explored the associated factors in a multiple regression analysis with "pain during activity" (NRS) as a dependent variable. The independent variables (educational level, pain location, pain duration, spread of pain, fear of movement/(re)-injury, emotional distress, self-efficacy and BMI) were first analyzed separately, and the significant factors were entered into a backward multiple regression analysis. Age and sex were added to the model as these are factors known to influence pain. Linearity and multicollinearity were checked.

We then analyzed the likelihood that participants would report pain during activity. The dependent variable was operationalized as dichotomous measures, where responders answered "yes" or "no" to questions whether they experienced increased pain during general activity and exercise. The questionnaires concerning pain related to general activity and exercise were answered and analyzed by 222 and 215 respondents, respectively. Logistic regression analysis (Backward Wald) was used. Pearson's correlations coefficient and linearity of the associations for the predictors were studied. Firstly, educational level, pain variables (pain location, pain duration and spread of pain), BMI and psychological factors (fear of movement/(re)-injury, emotional distress and self-efficacy) were analyzed in univariate analysis, including age and sex. Then the significant factors ($p < 0.05$) as well as age and sex were entered into a Backward Wald analysis. Logistic regression analyses were carried out in the whole study sample, and in a subgroup with scores on HSCL-25 indicating non elevated level of psychological distress (mean sum-score/25 < 1.70). A significance level was set at 0.05.

Results

Characteristics of participants

Thirty-one percent (n = 73) of the participants reported mainly neck / shoulder / arm pain, 47 % (n = 110) reported low back / leg pain, and 22% (n = 49) reported multiple pain sites. Seventy-five per cent (n = 176) of the participants had previously attended physical therapy including exercise. Fifty-two per cent of them reported short time relief while 40 % reported no relief. Descriptive data on demographics, Body Mass Index (BMI), leisure time physical activity, pain and psychological factors are presented in Table 1. There were no significant differences between participants (Table 1) and consenters with uncompleted questionnaires regarding age (42, SD 10), sex (50 % female) and education (primary school 13 %, vocational training 48 %, high school 14 % and university education 25 %). Compared to non-consenters, participants had a higher educational level and included more men (non-consenters were 76 % female), while there was no difference in age.

Psychological factors

Psychological distress, as evaluated by HSCL was elevated ($\geq$ 1.70) in 51% of respondents (mean 2.14, SD 0.38), and was similar in men (mean 1.78, SD 0.50) and women (mean 1.78, SD 0.47). Self-efficacy was similar in men (mean 4.5, SD 2.1) and

women (mean 4.2, SD 1.6), while fear of movement/ (re)-injury was significantly higher in men (mean 32.1, SD 7.6) than in women (mean 28.4, SD 6.8) ($p < 0.05$).

The occurrence of activity related pain

The participants reported a significant increase in pain intensity (NRS) from rest to activity (1.6, SD 2.4), ($p < 0.001$). Pain at rest and pain during activity was positively correlated ($r = 0.56$, $p < 0.001$). Increased pain during activity (NRS) was reported by 69% ($n = 160$) of the respondents, at a mean value of 2.5 (SD 1.6). Among these 48 (30%) participants reported neck/arm pain, 79 (50%) reported low back / leg pain and 33 (20 %) reported multiple pain sites. In analyses of patients who reported increased pain intensity during activity (NRS) (69 %) compared to patients who reported no change or decrease in pain during activity (NRS) (31%), no group differences were reported with respect to sex, BMI, self-efficacy, emotional distress or fear of movement/(re)-injury. Age was significantly higher in patients who reported no change or decrease in pain during activity, compared to patients who reported increased pain intensity during activity.

Pain at rest was significantly higher in patients with multiple pain sites (mean 6.5, SD 2.3) than in patients with low back / leg pain (mean 5.4, SD 2.4, $p < 0.03$) while pain during activity (NRS) was reported similar across patients in different pain categories: Multiple pain sites (mean 7.6, SD 2.2), low back / leg pain (mean 7.2, SD 2.2) and neck/shoulder/arm pain (mean 7.0, SD 1.8). Pain during activity (NRS) was reported significantly lower among participants at the highest level of leisure time physical

activity (mean 6.25, SD 2.30) compared to participants at the moderate level (mean 7.3, SD 2.1, p = 0.03).

Increased pain during general activity (dichotomized variable) was reported by 66% of the participants. Seventy-five percent of them reported increased pain at activity also on the NRS, and the rest reported no change in pain from rest to activity (NRS).

Pain during activity

Pain during activity (NRS) was the dependent variable. Fear of movement/(re)-injury and pain at rest (NRS) remained in the final model (table 2), explaining 36 % of the variance in pain during activity (NRS).

Increased pain during general activity and exercise

The dichotomous variables asking for increased pain during general activity and exercise were dependent variables. The univariate logistic regression analysis showed that spread of pain, fear of movement / (re)-injury, psychological distress and self-efficacy were significantly associated with the likelihood of reporting pain during exercise and general activity. Pain at rest was significantly associated with the likelihood of reporting pain at general activity (OR 1.17, 95% CI 1.03 – 1.32, p = 0.01), but lost significance in a multivariate analysis.

As shown in table 3 fear of movement / (re)–injury emerged as significantly associated with the likelihood of reporting increased pain during general activity and

exercise in the final model. Spread of pain was more strongly associated to pain during general activity and self-efficacy more strongly associated to pain during exercise in this model (Table 3).

Associations in a sub group with non elevated level of psychological distress

As we were interested in the concurrent properties or differences between fear of movement/(re)-injury and psychological distress in predicting pain during general activity and exercise, these two variables were then tested in one model. In this model fear of movement / (re)-injury remained significantly associated with reporting increased pain during both exercise (OR 1.09, 95% CI 1.05 – 1.13, $p < 0.001$) and during general activity (OR 1.07, 95% CI 1.03 – 1.12, $p < 0.001$).

If fear of movement/(re)-injury were a construct significantly different from psychological distress, the result from our previous analyses with respect to fear of movement / (re)-injury would be replicated in a subgroup with non elevated levels of psychological distress (n = 114). The result from these analyses showed that fear of movement/(re)-injury remained a significant predictor in this subgroup for increased pain both during general activity ($p < 0.001$, OR 1.07, 95% CI 1.03 – 1.12) and exercise ($p < 0.001$, OR 1.08, 95% CI 1.03 – 1.13).

Discussion

Occurrence of increased pain during activity

This study appears to be the first to assess the incidence of increased pain during activity in a sample of patients with local and generalized muscle pain. As anticipated, the majority of the participants reported increased pain. However, two points are worth noting. First, 31 % of the population reported no change, or decreased pain intensity during activity. Second, the mean value of increased pain was fairly low; suggesting that some patients reported increased pain during activity as modest.

Associations between psychological factors, pain variables and increased pain during activity

Fear of movement / (re)- injury was the factor found to be associated with increased pain during activity across two different analysing methods. It is noteworthy that this was despite the fact that there were no differences on the TSK between participants reporting increased pain and those reporting no change or decreased pain during activity.

The role of fear of movement / (re)-injury in increased pain during activity may be of a mediating nature, meaning that fear increases the perceived pain [46]. As well, it is likely that increased pain increases fear and that fear and pain is mutually reinforcing. The likelihood of reporting pain during exercise increased with 8 % per unit in TSK. Participants in this study presented with a high level of fear of movement/(re)-injury, thus

we can assume that the clinical significance of fear of movement/(re)-injury concerned patients with high levels of such beliefs. However, fear of movement/(re)-injury has not proven stable as a predictor of pain and function, and may as well be a consequence of pain during activities [47]. As anticipated, psychological distress was correlated with fear of movement/(re)injury. The elevated level of psychological distress in this study sample is in concordance with other studies [4; 22]. However, our study did not reveal psychological distress as significantly associated to increased pain during activity. Fear of movement / (re)-injury remained significantly associated with the likelihood of reporting increased pain during activity also in a subgroup of subjects with a non elevated level of psychological distress. These results indicated that fear of movement / (re)-injury may develop regardless of an individual's level of distress and somatisation. Thus, fear of movement/(re)-injury seems to be a different construct than general anxiety and may as well reflect a rational behaviour to avoid painful movements. The sense of self-efficacy also had a modest, but significant role in predicting the likelihood of reporting pain during exercise. A lower sense of self-efficacy was significantly associated with reporting pain during exercise, which could indicate that the pain experience during exercise is of a different nature than the one of general activity. Fear of movement / (re)-injury and self-efficacy have emerged as important factors regarding function and disability, especially in patients with low back pain [48;49], and this study adds information about the contribution of these factors in perception of increased pain during activity. It is discussed whether some patients become disabled partly because of low self-efficacy beliefs; the person's doubt in own ability becomes a self-fulfilling prophecy [48]. The data in this study bring some support to the notion that trust in own ability to manage

pain influences a person's perceived pain and render it less threatening. However, less pain is also less threatening, and less pain during exercise may increase perceived control over pain and thus influence self-efficacy. In this perspective the association between the pain experience during exercise and perceived control over pain (pain self-efficacy) may also reflect how some patients continue to exercise despite pain. In a recent study, Mannerkorpi and associates found that patients associated physical activity with well-being and health, even if pain increased as a result of physical activity [50]. In some studies, the impact of psychological factors seems to vary across patients with different localizations of pain [51]. However, in the present study localization of pain was outweighed by fear of movement / (re)-injury in the prediction of pain during general activity and exercise.

Interestingly, multiple pain sites did not have an impact on reported pain on activity while spread of pain emerged as a significant factor for the likelihood of reporting pain during general activity. An 8 % increase for each unit in this case must be considered significant. It is known that having pain in one site enhances the risk of developing pain in other sites, indicating a spread of pain over time [52]. It is also known that patients with fibromyalgia report increased pain during physical activity, and it is suggested that the phenomenon is of the nature of altered central pain mechanisms [53]. The associations between widespread pain and increased pain during activity in patients with musculoskeletal disorders may as well reflect central sensitisation. In agreement with findings in this study, Bunketorp and colleagues found that pain location was not significant for pain disability, but the more widespread pain and the more negative

emotions connected to pain, the more it interferes with the person's ability to function in daily and recreational activities [17].

Clinical implications

Pain related to activity may be one of the reasons why patients stop exercising and decrease their activity. This study provides knowledge which will be valuable in clinical settings including patient education. Measuring and discussing increased pain during activity with patients seems to be of importance, to identify patients for whom this phenomenon is a significant problem. The level of self-efficacy and fear of movement / (re)-injury may serve as prognostic tools for the outcome of exercise based rehabilitation. Treatment including cognitive approaches to strengthen patients self-efficacy and lower fear of movement/(re)-injury, for example by cognitive behavioural therapy may be promising in some patients for whom this is a problem [10;54].

We also suggest a more targeted treatment based on the individual patient's problems and needs. Questions to be discussed with patients are: Is painful physical activity a problem? Is fear of movement / (re)-injury a problem? Is the pain problem local or widespread? A thorough clinical examination is necessary to rule out conditions where activity should be limited, like some acute injuries. Research within the field of fibromyalgia suggests that activity-related pain is of a different nature with respect to neuromuscular functioning than the chronic widespread pain [55]. Vollestad and Mengshoel conceptualize this type of pain as acute pain within a chronic pain course. This understanding of pain related to exercise should be considered in patient educational

programmes and patients should be informed about possible pain increase if exercising is part of rehabilitation. It will be helpful for patients to know about the nature of this pain, and be prepared for it. Unexpected pain during activity could provoke fear and focus on the pain, making patients restrict exercise [56].

Strengths and limitations

The strength in this study is that data are collected from a large number of patients, representing a broad spectrum of musculoskeletal disorders. All subjects regardless of pain localizations were included. A rational for this approach was that coexistence of musculoskeletal pain from different locations is high [57] and pain is better represented on a continuum from localized pain to widespread pain [52]. This is supported by the present study, as spread of pain was significantly associated with increased pain during general activity and pain localization was not. For this reason, Natvig [57] recommends treating subjects with musculoskeletal pain as one sample in research, and this methodology is common in multiple regression models [58]. In addition, investigating subsamples with different pain sites, would have limited the possibility to test several factors in a multiple regression model, due to low numbers of subjects in each group [59].

The consent (48 %) and participation rate (43 %) limits the study. Another limitation is that participants had a higher educational level and included more men than non-consenters. This may have influenced the results, as fear of movement / (re)-injury was significantly higher in men and education is associated with muscle pain [60]. In line with this, a lower proportion of high school and university/college education was found

in our respondents than in the general population or the county of residence. However, the educational level in the present study is comparable with other studies with similar populations [61;62]. Another limitation is the assumption that pain perception during activity as well as pain-related fear of movement / (re)-injury is contextual. Social and cultural factors appear to be of significance [63;64] and previous exercise experiences and learning contribute to changes in the expectation of physical activity as dangerous and pain-provoking [10]. These issues were beyond the scope of the present study.

The use of a dichotomized variable asking participants to answer ‘yes’ or ‘no’ may be questionable, as it may lead the participants to answer ’yes’. Methodological incongruence may also be reflected in the fact that the overlap between participants who confirmed the presence of increased pain during general activity and participants who scored increased pain on NRS was 70 %. Another possible explanation to this phenomenon is that patients’ experiences of increased pain during activity reflects more than the sensational experience of pain, and thus describe presence of pain despite that no increase in pain intensity (NRS) is reported. However, fear of movement/(re)-injury was the final associated factor found across two methods for assessing pain during activity, which we believe to strengthen the finding of this variable’s significance.

The design used in our study was cross-sectional, thus causal relationships cannot be determined. Our data was based on patients’ self-reports and the terms ‘exercise’ and ‘general activities’ as used here offered different interpretation possibilities. However, data on individual’s beliefs and perception of pain are only available through self-reports.

Conclusion

In this study increased pain during activity was reported by a majority of the participants. High levels of pain-related fear of movement / (re)-injury was associated with increased pain during activity, also among individuals with non-elevated levels of psychological distress. More widespread pain and a lower sense of self-efficacy were also factors associated to the likelihood of reporting increased pain during activity. To establish knowledge about causal relationship between behavioural factors, self efficacy and pain during activity longitudinal studies would be helpful.

Declaration of interest:

There are no conflicts of interest

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Table 1 Characteristics of participants (n = 232)

Background data	**Study sample**
Age (Mean, SD)	42 (10.0)
Sex (female) (n, %)	124 (53)
BMI (Mean, SD)	27.8 (16.7)
Education (n, %)	
- Primary school	46 (20)
- Vocational training	92 (40)
- High school	26 (12)
- College / university	65 (28)
Working status (n, %)	
- Working	64 (32)
- Sick leave < 12 weeks	12 (6)
- Sick leave 13-52 weeks	53 (27)
- Rehabilitation or disability pension	69 (35)
Leisure time physical activity (n, %)	
- Sedentary	32 (14)
- Moderate	169 (73)
- High / Very high	31 (13)
Pain duration (n, %)	
< 6 months	1 (0.4)
7-12 months	22 (10)
13-60 months	101 (47)
61-119 months	43 (20)
> 120 months	50 (23)
Pain intensity at rest (NRS) (Mean, SD)	5.6 (2.4)
Pain intensity on activity (NRS) (Mean, SD)	7.2 (2.4)
Spread of pain (squares on pain drawing, range 2 – 86) (Mean, SD)	16.5 (11.8)
Fear of movement, TSK (Mean, SD)	30.3 (11.9)
Psychological distress, HSCL 25 (Mean, SD)	1.79 (0.48)
Self-efficacy, ASES (Mean, SD)	4.3 (2.1)

Table 2. The relationship between the predictive factors and reported pain during activity (NRS) explored by multiple regression analyses. In the final model pain at rest (NRS) and fear of movement/ (re) injury remained significantly associated with reported pain during activity. P-values for adjusted B (CI) in the final model are provided.

	B	CI B	p	Adjusted B	CI Adjusted	Adjusted p
Educational level	- 27	0.50 – 0.60	0.01			
Pain Location	0.10	-0.25 – 0.45	0.58			
Duration of pain	0.24	- 0.05 – 0.52	0.10			
Spread of pain	0.25	0.00 – 0.48	0.03			
Body Mass Index	6.90	6.35 – 7.43	0.21			
Psychological Distress	1.28	0.66 – 1.77	0.001			
Self efficacy	- 0.05	- 0.08 – -0.03	<0.001			
Pain at rest	0.50	0.41 – 0.60	<0.001	0.48	0.40 – 0.58	<0.001
Fear of movement	0.70	0.34 – 0.10	<0.001	0.60	0.30 – 0.90	<0.001

Table 3. Logistic regression (Backward Wald) prediction for the likelihood of reporting increased pain during activity, given the influence of predictive factors. The final model with the odds ratio (with 95 % confidence intervals) for the likelihood for each factor and p –values are given.

Predictive Factors	Increased pain at general activity (n = 222)			Increased pain during exercise (n = 215)		
	OR	CI	p	OR	CI	p
Spread of pain	1.08	1.04 – 1.12	< 0.001	1.03	0.10 – 1.05	0.83
Self efficacy	0.98	0.94 – 1.01	0.18	0.95	0.92 – 0.98	< 0.001
Fear of movement	1.08	1.08 – 1.03	< 0.001	1.08	1.03- 1.29	< 0.001

Paper 3

Resubmitted to *Scandinavian Journal of caring Science*

STAYING ACTIVE DESPITE PAIN

Pain beliefs and experiences with activity-related pain among outpatients with chronic musculoskeletal pain

E. Damsgård [1*], A. Dewar [2], C Røe [3], T. Hamran [4]

[1]*Cand. San, RN, Department of Health and Care Sciences,*
University of Tromsø, N-9037 Tromsø, Norway

[2]*Associate professor, PhD, RN, University of British Columbia, School of Nursing,*
T 254-2211 Wesbrook Mall, Vancouver BC, Canada

[3]*MD, PhD, Department of Physical Medicine and rehabilitation,*
Ullevål University Hospital, Oslo, Norway.

[4] *Professor, PhD, RN, Department of Health and Care Sciences,*
University of Tromsø, N-9037 Tromsø, Norway.

[*] *Correspondence:*
Elin Damsgård
Department of Health and care Sciences
N-9037 UIT
Telephone: + 47 77 64 69 24
E-mail : Elin.Damsgard@uit.no

CONTRIBUTIONS:

Study design: ED, CR, TH, Data Collection: ED, Data Analysis: ED, TH, AD. Drafting of manuscript: ED, Critical revision and supervision: AD, TH, CR.

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ABSTRACT

Objective: Maintain a level of activity and exercise is advice often given to patients with chronic musculoskeletal pain, but many patients find physical activity painful and, consequently hesitate to move. Disability seems to be associated with fear of pain and there is a need to enhance our understanding of patients' beliefs and attitudes about how fear of pain affects physical activity and why some people are active despite their pain. The aim of this research was to understand thoughts and experiences about pain related to activity in patients with musculoskeletal disorders; the situations that promoted pain and if and how fear was expressed.

Methods: Five women and five men, recruited from a larger survey on fear, pain and physical activity were interviewed. The interviews were analyzed by qualitative methods for themes about participants' pain and beliefs about pain.

Results: By interpreting signals from the body, patients calculated and planned their daily life to stay active despite pain, and participate in their social lives. Pain was a signal with diverse meanings which, with the influence of time, seemed to change from a sign of danger to a reminder to moderate their level of activity. By experimenting with different activities, patients learned how to gradually remain or become physically active.

Conclusion: Patients strived to stay active despite pain. The interpretation of pain changed over time, from a threatening signal to a signal with diverse meanings.

Practice implications: The findings provide insights that may improve the educational rehabilitation of patients with musculoskeletal pain.

Key words: Muscle pain, physical activity, pain beliefs, fear avoidance, qualitative research.

INTRODUCTION

Chronic musculoskeletal pain is a common condition that negatively affects many aspects of peoples' lives and is one of the most frequent reasons for disability pensions in Norway (1). Patients' beliefs, experiences and actions associated with pain are significant factors that contribute to pain perception (2;3) and hence are important in our understanding of pain development and management. In the rehabilitation of patients with chronic muscular pain, staying active is important and exercise is often proposed as a treatment modality (4;5). However, common clinical observations indicate that patients report increased pain during exercise and activities of daily living. Research has described how patients with low back pain restrict their physical activity because they are afraid of provoking pain (6), and that low back pain, even when described as moderate, forces patients to be aware of movements and physical activity (7).

Inactivity among individuals with musculoskeletal pain may be explained by pain-related fear of physical activity, and several quantitative studies have investigated the relationship between pain related fear and disability (8;9). From a theoretical perspective, the fear avoidance theory offers one explanation about how musculoskeletal pain transitions from acute to chronic pain and brings about disability (9;10). In essence the interpretation of an injury, or a pain experience, varies between individuals. If pain is interpreted as very threatening then some individuals may develop pain-related fear of physical activity and avoid activities and/or become hyper vigilant to situations that provoke pain. This interpretation of pain as fearful can eventually lead to disability (8;10). As a consequence, rehabilitation as well as general activities and work may become difficult, bringing patients into a vicious circle of pain, social withdrawal, depression and inactivity (10;11). However, withdrawal from situations that provoke pain is a natural response and avoiding pain by limiting activity may be a rational behavior (5). As well, it is likely that pain intensity is an important reason for limiting activity (8).

Both psychological and physiological factors influence pain disability, and treatment often includes educational approaches as well as exercise (12;13). If cognitive approaches are to assist patients to cope with chronic pain, assessing and lessening fears associated with activity is important (8). In a recent survey of pain related fear and physical activity we found that patients who described increased pain during activity, still appeared to be physically active, and even exercised (14). This finding raised for us questions of what prompts people to maintain their activity despite pain. In the rehabilitation process of patients with chronic muscular pain, patients' attitudes and beliefs are important factors, and to determine the patients' perspectives, qualitative research methods are important (15). Researchers who investigate the experience of muscle pain indicate that pain restricts physical activity and that pain management related to physical activity is influenced by the norms of society (16;17). However, we lack information about patients' perspectives of activity and muscle pain and how fear is a part of it. Greater understanding in this area will contribute to health care professionals' knowledge about how to advise and assist patients to manage their pain. The aim of the present research was to understand more about activity related pain in patients with chronic musculoskeletal disorders, and also if and how fear is a part of it.

METHODS

Research methods as described by Malterud (18) guided this research. These exploratory methods were selected to enable the researchers to understand the participants' experiences and to interpret these experiences in a meaningful manner. Data were drawn from qualitative interviews (19) with outpatients at the Department of Physiological Medicine and Rehabilitation. Semi structured, open ended questions provided an opportunity for the interviewees to give detailed and rich descriptions of their experiences and beliefs concerning why they continue to exercise despite experiencing pain.

The study took place from the period of March to June 2006. In a previous survey (14), one hundred and twenty outpatients who attended this department consented to participate in a survey about physical activity and pain. Included in the survey package

were self report questionnaires about the participants exercise habits and whether they experienced pain during physical activity. Also included was an invitation to participate in a follow-up study to examine their experiences concerning activity-related pain in more detail. Of the one hundred twenty individuals, fifteen, who met the criteria described below, were invited to participate in the present study and ten gave informed consent. These were contacted by telephone by the first author and given additional information about the study before they were interviewed. The study was approved by the Regional Ethical Committee in Northern Norway (Number**:** 5.2005.828**).**

Participants

The participants were selected based on answers from a survey comprising demographic data, pain variables, standardized questionnaires, and questionnaires developed by the researcher on physical activity and pain (14). Participants were selected for diversity regarding duration of pain, pain location, exercise habits and pain during exercise and general activity. Both men and women were included as gender differences in pain are known (20) (Table 1).

Three participants had a college education, five had vocational training and two had high-school education. Six were married, three were divorced and one was single. Nine had children. Six participants were currently in a full time work; three were on sick leave, and one was applying for 50 % disability pension. One participant was taking an occupational retraining program. The participants had endured their pain from one to more than ten years. Two participants had undergone surgery for back pain. Four had participated in an exercise/learning group organized by the hospital's Department of Physiological Medicine. This group uses exercise as well as group discussions and educational tools as approaches to keep patients employed or returned to work.

[Please, insert Table 1 here]

Data collection and analysis

The interviews were held at a meeting room at the Research Center. One author ED, interviewed the participants using an open-ended interview guide (19). The guide was developed with thematic questions concerning pain related to general activity, at work and during exercise. The main questions were: 'Please try to describe your pain', 'Please try to describe your activities during an average day', 'In what situations do you feel the pain?', 'What are your thoughts and feelings about the pain?', 'What is the hardest part of being in pain?' Participants were also asked about family traditions, family history of pain, work and their experience with the health care system. They were encouraged to share their experiences by stories and examples. The interview guide functioned as a framework, but as issues arose then relevant concerns and related themes were explored. The interviews, which were approximately 60 minutes long, were audio-tape recorded and then transcribed verbatim by a professional secretary. Notes were taken during and after the interviews, and an audit trail was kept to have a record of the researchers thinking and demonstrate the rigor in the research methods (21).

Data (about 68 000 words) were analyzed using an interpretive approach, described by Malterud (18;22). The focus of the analysis was to look for the participants' descriptions and explanations of pain associated with different activities and how fear was expressed in these circumstances. The analyses started with the first four interviews. Following the principles described by Malterud (18) data were read independently, and then discussed, by two of the authors (ED and TH) to obtain an impression of the main themes (22). These themes were pursued during the subsequent interviews. Each interview was searched for meaning units, which represented relevant aspects of the participants' experience with activity related pain. The meaning units formed codes which captured phenomena in one or a few words. The data within each code was further condensed and compared within and across interviews to form categories (22;23). To structure the data re-reading and discussing alternative interpretations were necessary analytic strategies. An iterative process, meaning moving back and forth between design and the data was

used throughout the whole research process (22). An example of analysis illustrating the development of the subcategories and categories is presented in Table 2. A preliminary summary of findings were read and discussed by three authors (ED, TH and AD). Peer discussions were held throughout the analyzing process, also with other members of the research team who were not data collectors. Discussions were also held with the health professionals who treated the patients at the Department of Physical Medicine including physiotherapists and physicians, and researchers from other professions. Finally, each interview was re-read to assure that all important patterns had been captured. The data were saturated meaning that findings about the explored phenomena were rich (24) and no new data emerged from re-reading of the interviews.

[Please insert table 2 here]

FINDINGS

The major theme was *staying active despite pain* and the three sub themes were *interpreting signals from the body, from uncertainty to self-knowledge* and *participating in social life*. This major theme best described why, despite sometimes increased pain during physical activity, most participants continued to be active through exercise, leisure time activities and work.
Table 3 shows the relationship between the subcategories, categories, subthemes and the main theme.

[Please insert table 3 here]

Interpreting the signals from the body

Pain was a signal from the body to self, and was subject to ongoing awareness and interpretation. When pain was associated with physical activity, it was mainly understood as a physiological problem rooted in body dysfunction. Whereas, sometimes general everyday pains were described as connected to 'stress' or 'tension': "In a work situation when I feel uncertain and nervous I really feel my muscles strike" (No. 7). A single mother, struggling with finances said:

> I do not get afraid [when pain is strong…] but everything that's hard and difficult becomes even more hard and difficult. And when it really hurts I think to myself: 'you're struggling with a lot here now, X [saying her name]'. (No. 6)

This participant attributed her pain to both physical and emotional causes. She described in detail the bio-mechanical structures in her painful area, and explained how bone rubbed against bone during physical activity. As well as a physical cause, she explained the close connection between pain and her bad feelings about her life. This dual explanation of the physical and emotional causes of pain was common among patients with a long history of pain.

Differentiating between the 'body' and 'me'

When the participants described the relationship between their pain and their bodies, they used terms such as 'take the signals' and 'my body tells me'. There seemed to be a 'real me' and a 'body me' and it was important for the 'real me' to listen to the 'body me'. These signals had diverse meanings and learning about them was an important aspect of staying active. To understand the meaning of the pain signal, it was important to 'read the signs' correctly.

> I have been biting my teeth and going on. And maybe that's a mistake; I haven't been reading the signs well enough. (No. 5)

Negotiating with the 'body me'

Some participants described how they tried to overrule the body by ignoring the signals, and in that case there was a dialogue between the 'body me' and the 'real me.' If the body signal was ignored, it could have serious consequences as the pain could intensify. One participant indicated that she refused to pay attention to her body hoping this would diminish the pain:

> The pain is my enemy and I don't need to talk to my enemies. I imagine that if I don't give it response it will not answer back to me. (No. 1)

Conversely, she described how she learned to recognize the pain not so much as an enemy, but as a signal to move or to calm down. In response to this signal, she choreographed her movements during work and activities of daily living so that she could carry on with her activities:

> If I have been sitting on the couch too long I get a signal from the body saying: 'Now you have spent too much time on the couch, you have to get up and do something. My body tells me that it is enough. (No. 1)

Attending to the body was a process of learning about when to extend oneself and when to rest. Self-critique sharpened attention to pain symptoms while participants learned that signals from the 'body me' cannot be overruled.

From uncertainty to self knowledge

Participants indicated that the influence of time, experimenting and learning about their pain were moderating factors in developing an understanding about their pain and lessening their fear of activity.

Influence of time

Initially, pain signified potential danger. Participants who experienced a sudden onset of intense pain were frightened especially when the pain was followed by other symptoms, such as numbness. "When this first happened to me I thought: Will I ever walk again?" (No.10). Over time, the interpretation of pain seemed to change. Participants who experienced long term pain with exacerbations and remissions, interpreted activity related pain as a signal to rest, and pain in general as a response to emotional distress. When participants were uncertain about the meaning of the pain signals and when they considered the future, they became fearful. When this participant was asked if she ever felt frightened about her pain, she answered:

> Maybe a little bit. You think – will it pass or not, things like that. But I have a sense of humour that helps me. Sometimes I bend over, and I'm stuck − I cannot rise again. And then I laugh rather than get afraid, because I know it will pass. A little more, maybe, [afraid] when I think about….. Will the pain ever go away? (No. 1)

Experimenting, developing trust & acquiring knowledge

As pain lost some of its threatening power, some participants indicated that they experimented and learned what worked. From this experimentation, they learned to trust their bodies. When physical activity was perceived as beneficial, they eventually established an exercise routine even if it contradicted the health care professionals' advice. In those situations their bodily experience overruled medical advice, and provided the guidelines to improvement.

> I was supposed to take it easy…, but you have to be moving. Being stuck in a chair made the whole thing worse… Moving – whatever sort of activity… To me it worked well to stay active, so that's what I did. (No. 8)

To some, the hospital's treatment group also provided skills and knowledge which diminished participant's uncertainty:

> It was really good to learn that you have to find out for yourself what you can manage… The way I understand it, I won't destroy anything in my body [by being physically active]. (No. 7)

Seeking explanations

Uncertainty about the meaning of pain signals made participants worried about the safety of their physical activities. The participants, especially in the early part of their pain experience, were looking for explanations and objective proof about what caused the pain. A physical explanation (such as an X-ray showing a herniated disc) was described as a "tremendous relief…., like a 100 kilos fell off my shoulders" (No. 8). A diagnosis, especially if accompanied by objective proof, seemed to provide participants with an incentive to learn as well as legitimizing their pain. The previous quote is from a man who waited for 5 months to get an X-ray. When asked why he did not read about his condition earlier he answered: "What would I read about? I did not know what it was."

Participating in social life

Pain and social situations

Pain affected many social situations and social roles. The amount of pain that participants were willing to endure was related to how important that activity was to their social roles. Male participants valued work and being regarded as trustworthy employees able to support their families. The women were particularly concerned that children did not suffer because of their mother's pain. A single mother, with a long history of back-pain, was dejected about the amount of time and effort she put into being a 'normal' mom:

> I am not a person who easily gives in. That's why I think it is so unfair − why me? There are so many things I could have done. And this pain ruins

> so much [for me]. I have been suffering through many camping trips with my children. (No. 4)

By calculating and planning all daily activities, physical or otherwise, participants ensured their ability to participate in social and occupational roles. All activities, from basic daily routines to major events, were gauged to consider the intensity and duration of pain that might follow. Attending to pain symptoms and calculating how to do the necessary everyday tasks with minimal pain consumed considerable energy and time. Depending upon the nature of the activity, sometimes they chose pain as an acceptable risk.

> Sometimes I know maybe I have lifted something heavy and though I try to do it carefully, I know the risk about the following day being painful. But then I think; that's OK, yes…. I know it is happening and I have to cope with it for a day or two, and then it's over. (No. 3)

Experiencing benefits of physical activity

Several participants described their childhoods as physically active, and they were accustomed to outdoor activities such as skiing and hiking. Consequently, they tried to exercise on a regular basis and described a variety of activities including swimming, biking, and weight-lifting. Some participants also described that during a period of physical activity pain would disappear. Walking was their main exercise which seemed to bring relief through gentle movement and gradually warming muscles.

While some of the participants considered exercise as a pleasure in itself, others were more concerned with the exercise as a beneficial activity and part of a healthy lifestyle. Several participants had parents and siblings with similar pain problems. This familial tendency was a concern as they feared their children would suffer similar pain problems. A father, who suffered from back pain, commented that his son had a similar complaint, but he 'kicks him out to play', as his mother did to him as a child.

Differentiating the quality of pain

Exercise-related pain had a contextual aspect as participants were able to differentiate between pain during exercise, activities of daily living and work. This phenomenon was most evident when the work situation was sedentary, stressful or required heavy lifting. For example, two of the most active participants lifted weights for exercise, but both complained that lifting at work was painful. When pain occurred in an exercise situation, it was often a familiar and anticipated phenomenon and was viewed positively.

> The pain is very different, depending on where I feel it, from which part of the body. None of them [bodily pain] feels good. It's a totally different thing if I exercise. Those are good pain[s]. (No. 1)

DISCUSSION

Interpreting signals from the body

Pain in everyday life may have diverse meanings, and a common perception is that pain is a sign of damage and thus danger (25). The interpretation of pain as a dangerous sign indicating damage may be a serious threat to self, and making a distance between the pain and self may bring consolation (26). Osborn and Smith in their research of the experience of low back pain described how pain in everyday activities is a reminder of the painful body, hence the painful body is dejected or alienated, to preserve the preferred self. They introduce the construct 'Not me' to describe how the painful body or body part is separated from self. This concurs with our findings of the 'body me' (Not me) and the 'real me' (preferred self). In our findings as well, sometimes making a distance between the 'body me' and the 'real me' seemed to provide a strategy to manage pain related fear. However, the negotiation between self and the body – the ongoing symptom attention, interpretation and activity regulation – seemed to be a way to include the body and the body's language (pain) as a part of self. Negotiation implied the recognition of the body's signals, and the possibility to act upon these signals. Thus, interpreting signals and

negotiating with self seemed to enhance the participants' perceived control, thus reducing fear related to activity.

From uncertainty to self-knowledge

An interesting result is participants' descriptions of learning by experimenting and through their own bodily experience. The learning process involved the re-interpretation of pain signals from dangerous to other diverse meanings. According to the theory of fear avoidance a vicious circle of pain and activity avoidance develop in some pain sufferers contributing to the chronification of pain and physical disability (10). Fear is a natural reaction to pain, and the meaning of pain influences how it is experienced (27). To re-interpret pain as a non-dangerous signal thus is a challenging change. The importance of personal bodily experience is described by other researchers, who emphasise how (positive) bodily experience and reflecting upon those experiences can open new perspectives and provide incentives to change and to learn to make your own limits (28-30). For many participants the main incentive to change their perceptions of activity related pain was to experience what they were able to do, despite pain, and how they were able to manage more successfully as time passed. For participants in this study, fear of pain consequences seemed to be most evident during their first experience of pain. Thus it seems like fear of movement was a result of pain provoked by activity, and the fear diminished as they learned how to cope with pain.

Participating in social situations

Participants placed a high value on being able to participate in social situations but this presented a dilemma as they were conflicted between the desire to be taken seriously as a person with special needs and the desire to be included in social situations as a healthy person. To be considered a person with special needs, they had to present symptoms – show their pain and discuss it. Being too 'sick', however, would exclude them from their social roles and emphasize their limitations. For most part, participating in their social

life outweighed pain related fear of activity, but calculating the pain and planning activities of daily living was a necessary strategy. In this contextual perspective low back pain as an example has been described as ‘an ongoing process, conditioned by the relationship between the person and his/her environment’ (3)(p.29). The concept ‘field of disease-actions’ describes how individuals develop an understanding of how to manage the disease by self-monitoring and regulating activity and thus controlling its manifestations and symptoms. Attention to symptoms in different social situations helps build personally valid disease models, based on everyday life. Different situations in every day life, that demand involvement in the sense of an activity, contribute to an individual’s changing life story (3). In this perspective the findings in this study indicate that staying active represents an important and pervasive tradition that enables individuals to express joy in living, be determined to carry on despite the pain, and is the key to participation in valued life roles. Through symptom attention and by modifying activities participants were able to take part in leisure time and other general activities despite, at times, paying the price of increased pain. Similar findings are presented by Borell et al who describes how chronic pain sufferers endure pain to be actively engaged in various social contexts with, and for, others (31). Not complaining and doing your best to participate were recurrent themes among participants in the present study as well.

Staying active despite pain

Despite some uncertainty about how to interpret the pain, the participants remained physically active, although sometimes they moderated their activities. When they did restrict their movements, it was a calculated choice that weighed the importance of an activity against a predicted painful outcome. Thus, avoidance of pain in some situations was evident, but the question whether they avoided activity because of fear remains unclear. These results concur with others who found that avoidance of activity is rooted in the fear of provoking pain, not necessarily the fear of injuring the body, and thus maladaptive movement is established (7;32). Other studies present a more nuanced perception of pain related to movement within different cultures (16). Some participants perceived pain as less distressful

in exercise than in work situations. A proposed difference between exercise and the work situation is lack of control. At work, refusing or planning what and when you will lift is not optional as it is in a health-studio. It is reasonable to assume that being able to control the situation which normally provokes pain, reduces pain- related fear and consequently reduces perceived pain (33;34). Fear of pain, as well as fear of the unknown is common in many situations (35;36).

IMPICATIONS FOR PRACTICE

Fear of pain is a phenomenon that may be expressed through variable experiences, and worries and fear for the future evidently is important to patients with chronic musculoskeletal pain (37). If fear of pain associated with the future is a barrier to activity, it is important for patients to learn that activity does not ruin the body. Results in this study indicate that time and learning played a role in moderating the fear of pain and movement. The combination of learning and group participation may decrease pain and fear of movement as well as strengthening the ability to manage pain through increased physical activity and trust in personal experience (12;38;39). Therefore, discussions and practicing in the context of guided group treatment may offer a chance to reflect upon what symptoms mean and how they can be managed. Having a diagnosis, or at least an explanation for their pain, may be the first step in making meaning out of an unclear and frightening situation (40).

Patient's expertise should be included in treatment regimes relevant to patient's everyday life. Cultural norms and values may well be influential in the interpretation of painful physical activity, and should be taken into consideration when addressing this issue in the clinical setting. The participants in our study mentioned walking and taking part in outdoor life as a main leisure time physical activity. These are activities which seem to be preferred in the general population in Northern Norway (41), and may be well suited in rehabilitation treatment. If possible, work situations should be modified to include choice and control as these were important to the participants. Patient's own histories should be an integrated part of caring for patients with musculoskeletal pain. Health care provider's disbelief in patient's

competence to make decisions on their own behalf may occur as a significant problem to patients with chronic illness (42). Failure to comply with medical recommendations may be a logical, rational and thoughtful process (40), and should be discussed respectfully with patients.

METHODOLOGICAL AND ETHICAL CONCIDERATIONS

The study's limitation and some of the methodological and ethical issues merit discussion. In qualitative research a relationship is established between the researcher and the participant; which presents some ethical problems. One potential problem may be the participants' expectations that they will receive help in some way (43). The researcher advised the participants that she did not provide any treatment and the interviews took place in a building separated from the clinic. Yet, the researcher's experience as a therapist made interviews sometimes challenging, as the role of the interviewer and the therapist is quite different, yet the same issues arise. The intimate atmosphere of an interview situation may lead participants to reveal information (19;43). In the present study, some participants gave information on private, sensitive matters. This information was not used, and confidentiality maintained throughout the research process.

Purposeful sampling gave diversity to the data with respect to the participant's pain and exercise habits (23), and the data were saturated in the sense that they gave rich descriptions of the phenomenon (24). However, for example patients with a shorter history of pain, and a follow-up interview, would have provided information especially about the time dimension, which seems important in this study. The semi structured interviews were suitable in this case, as the topic was defined, yet provided openness to deviate from the topic. Hence, thick descriptions of the participants' experience of activity related pain were obtained. However, as the pain experience permeated the participants' lives, it was sometimes challenging to define the most relevant data. The researcher who interviewed the participants, is a nurse experienced with pain treatment. This is a strength of the study's trustworthiness as it enhances the researcher's ability to capture the realities of the participants' stories (44).

However, it may also introduce some problems as the researcher will be influenced by previous knowledge and experience, and preconceptions are not always clear to the researcher. Peer discussions about alternative interpretations of the findings thus were important tools to enhance rigor in this study. To further address credibility in the interpretive process, categories and themes constructed from the data were linked to existing literature (24). This study took place in Norway, where staying active is regarded desirable as a life style and physical activity is promoted by health care authorities (45). We suggest that this is an important context when interpreting the results. However, musculoskeletal pain is a problem in many western societies and we think the results of this study may be transferable to similar settings.

CONCLUSION

There were two important incentives for participants to stay active despite pain. One was the experience and perception of physical activity as beneficial, and the other was that activity was the key to participating in social life. The participants' pain experience and interpretation of the pain signal, including fear, differed according to situation and time. Experimenting and learning seemed to make fear avoidance behavior less evident. This required symptom attention and activity regulation, thus calculating and planning became an integral part of everyday-life. Hence, a contextual view of pain related to physical activity and pain-related fear is supported by the findings. The different dimensions of pain-related fear should be further investigated to bring a deeper understanding of patients' perspectives.

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Table 1 Description of participants

Participants, gender and age	Main pain location	Duration of pain
Female, 31 years	Pelvic pain	6 years
Female, 39 years	Low back/leg	> 10 years
Female, 45 years	Low back/pelvic and neck	8 years
Female, 43 years	Neck/arm	4 years
Female, 50 years	Neck/arm	> 10 years
Male, 43 years	Neck/head	> 10 years
Male, 47 years	Neck/shoulder/breast/low back	> 10 years
Male, 36 years	Low back/leg	5 years
Male, 36 years	Low back/leg	6 years
Male, 33 years	Low back	1 year

Table 2 Example of analysis

Meaning unit	**Condensed**	**Subcategory**	**Category**
"And then I think…, when they explain this to me..that you are in pain because of this and that..I think that's fair. OK, I accommodate to that."	She accommodated to the situation when she had an explanation.	Following medical advice.	Experimenting and developing trust
"I was supposed to take it easy…but you have to be moving. Being stuck in a chair made the whole thong worse…Moving – whatever sort of activity… To me it worked well to be active, so that's what I did."	He was advised to take it easy, but stayed active.	Not following medical advice	
"So even, through many years, I have experienced that my back hurts; I do not get worse from it.. [activity]. It has always worked fine. That is why I know my body won't get injured even when I am by pushing myself, and I go on with it."	He experienced that it worked fine to be active, the back pain did not worsen	Learning from own experience.	
"It was really good to learn that you have to find out for yourself what you can manage…The way I understand it, I won't destroy anything in my body [by being physically active]."	He learned that he will not injure his body by staying active.	Learning from others	

Table 3 Categories and themes of activity related pain in patients with muscle pain

Sub Categories	Categories	Sub themes	Main theme
Pain as bodily dysfunction. Pain as emotional distress.	Differentiating between the “body” and “me.”	Interpreting signals from the body	Staying active despite pain
To do what the body tells you. Not to do what the body tells you.	Negotiating with the “body me”		
Fear of pain Fear of future	Influence of time	From uncertainty to self-knowledge	
Medical advice Learning from self and others.	Experimenting and developing trust		
Wondering about symptoms. Uncertainty.	Seeking explanations		
Taking care of the family. Being trustworthy at work. Doing what is expected. Accommodating to the situation. Managing by oneself.	Pain and social situations	Participating in social life	
Physical activity as healthy. Physical activity as necessary	Experiencing benefits of physical activity		
Pain at work. Pain on exercise. Pain at leisure time activities.	Differentiating the quality of pain		

Paper 4

Readiness to adopt a self management approach to pain – are profiles of subscale scores on the Pain Stages of Change Questionnaire useful?

Terese Fors, M.D.[1], Elin Damsgård, R.N. Cand. San[1,2], Cecilie Røe, M.D., PhD[3,4], Audny Anke, M.D., PhD[1,2].

[1]Department of Physical Medicine and Rehabilitaton, University Hospital of North Norway, 9038 Tromsø, Norway.
[2]Institute of Clinical Medicine, Faculty of Medicine, University of Tromsø, Tromsø, Norway.
[3]Department of Physical Medicine and Rehabilitation, Ullevål University Hospital, Oslo, Norway.
[4]Faculty of Medicine, University of Oslo, Oslo, Norway.

Corresponding author:
Audny Anke
Department of Physical Medicine and Rehabilitation
University Hospital of North Norway
9038 Tromsø
Norway
Tel: +47 95936333
Fax: +47 77628049
E-mail: audny.anke@unn.no

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Key Words: Pain stages of change questionnaire; Chronic pain; Pain self-management;

Abstract

The study aimed at evaluating the ability of the Pain Stages of Change Questionnaire (PSOCQ) to classify subjects with longstanding musculoskeletal pain into specific profiles of readiness to adopt a self-management approach to pain. An analysis was made of whether the five earlier described PSOCQ-profiles Precontemplation, Contemplation, Noncontemplative Action, Participation and Ambivalent could be reproduced by two different methods, visual inspection and cluster analysis with Wards method and a 5-cluster solution. The 184 included subjects completed the PSOCQ, the Hopkins Symptom Check List (HSCL-25), the Tampa scale of Kinesiophobia (TSK) and five self-efficacy questions from the arthritis self-efficacy questionnaire (ASES). Profiles were drawn based on the mean subscale scores of the four stages in PSOCQ. We found that cluster analysis was able to identify the three profiles Precontemplation, Contemplation and Participation. By visual inspection all the five predefined profiles were identified, although 17% of subjects could not be classified, and another 18% were rated as difficult to classify. As expected the two profiles Precontemplation and Participation seem to identify distinct subgroups that differ clearly in psychometric measures, while the Contemplation profile group has scores in between. It is concluded that the three profiles Precontemplation, Contemplation and Participation are the most robust, as they are repeated and could be identified by both methods. The visual method, i.e. to identify PSOCQ- profile by visual inspection, could be clinically useful, but was not promising as the only approach. Classification of subjects into three categories is suggested: A Precontemplation and a Contemplation subgroup determined by highest mean subscale score, and a Participation group with high scores on the action and maintenance subscales.

Introduction

Multidisciplinary chronic pain treatment programmes intend to improve a persons self-management skills in coping with a pain condition (Kerns et al., 1998; Morley et al., 1998; Van Tulder et al., 2000). Self-management treatment approaches challenge the patients to make substantial changes in both beliefs about pain and coping strategies toward pain. How motivated the patient is to engage in and to maintain the treatment recommendations will affect both the way a person carries out the programme, the outcome, and should determine the most effective clinical approach (Burns et al., 2005; Kerns et al., 1998; Kerns et al., 2000; Turk and Rudy, 1991).

Influenced by the Transtheoretical Model (TTM) and the cognitive behavioural perspective on pain management, Kerns and colleagues proposed a model for conceptualizing the process of adopting a self-management approach to chronic pain, and developed the self report questionnaire Pain Stages of Change Questionnaire (PSOCQ) (Kerns et al., 1997). The questionnaire measures the extent to which an individual accepts personal responsibility for pain control and is considering making behavioural changes to cope with the pain. It is comprised of four distinct scales: Precontemplation (belief that management of the pain problem is primarily the responsibility of medical professionals), contemplation (consideration of adopting a self-management approach but reluctance to give up a medical solution), action (beginning attempts to improve self-management skills), and maintenance (commitment to pain self-management) (Jensen et al., 2003).

A central challenge with PSOCQ is the problem of assigning patients to reliable stage groups. Studies have pointed out the relative lack of differences between persons identified as being in different stages, especially a high correlation between the action and maintenance scales (Carr et al., 2006; Dijkstra, 2005; Jensen et al., 2000; Kerns et al. 1997; Strong et al., 2002). Research has suggested that individual profiles of scores could be a more robust predictor of treatment response than relying on a participant's single highest subscale score (Biller et al., 2000; Jensen et al., 2000; Keefe et al., 2000; Strong et al., 2002). Kerns et al sought to identify reliable subgroups of patients based on profiles of all four subscale scores, and identified five profiles labelled Precontemplation, Contemplation, Noncontemplative action, Participation, and Ambivalent (Table 1) (Kerns et al., 2005). However, earlier reports have argued that perhaps people cannot be "staged" in discrete and stable patterns of readiness to self-manage pain, and previous studies with different research designs have given different results (Dijkstra, 2005). Accordingly the primary aim of the current study is to test the occurrence of PSOCQ-profiles in a new sample by two different methods. We

hypothesised that the five profiles described by Kerns could be identified, both by statistical cluster analysis and by visual inspection. Cluster analysis is a coarse statistical way to classify subjects with similar patterns of responding, and we predicted that not all profiles would appear statistically. Visual identification of profiles has as far as we know not been reported earlier, and we also wanted to assess the agreement between cluster analysis and visual inspection. Finally, we hypothesised that the profiles identified were associated with measures of pain belief and coping in agreement with the TTM and previous reports (Jensen et al., 2000; Kerns et al., 2005).

Methods

Participants

Participants were recruited from the "Neck and Back"-unit at the University Hospital of Northern Norway, Department of Physical Medicine and Rehabilitation in the period from October 2005 through October 2006. The clinic receives patients referred from primary health- care with various musculoskeletal complaints. Inclusion criteria were first time visit, understanding and speaking the Norwegian language, and age between 18 and 67 years. Patients with suspected malignant diseases were excluded. In this period 549 eligible patients were referred, about 5% did not meet the inclusion criteria and were excluded, and 263 gave informed consent. One hundred and eighty four patients with complete registrations in PSOCQ were entered into the study.

The average age of the participating patients was 41.5 (SD 9.8, range 19-66) years, and 95 (53%) were female. The subjects underwent a clinical examination and comprised patients with painful conditions with different ICD 10 diagnoses in chapter M00-M99. Based on both clinical examination and pain drawings, they were categorized as: Neck/ shoulder/ arm pain n= 56 (30%), Low back pain n= 82 (45%), Multiple pain sites n= 40 (22%) and Local pain n=5 (3%). All respondents reported pain symptoms for at least 6 months, 90% had had pain for more than one year and 23% for more than 10 years. Nineteen percent had primary school education, 40% had vocational training, 11% had high school education and 30% had college/ university education. At the moment of the study, 30% were on sick leave, 32% were in a rehabilitation or re-education programme, 28% were working or unemployed and 6.5% had retired.

The 263 subjects who consented to participate were compared with the non-consenters. Consenters included more men (47%) than non-consenters (24%), and had significantly higher educational level (primary school 20%, college/university 28% vs primary school 36%, college/ university 24%).

The 184 with complete registrations of PSOCQ who were finally entered into the study, had a statistically significant lower age (41.6 vs 45.1) ($p=0.02$) and higher educational level (primary school 19%, college/ university 30% *vs*. primary school 34%, college/university 23%) ($p<0.05$), than those 79 consenters with incomplete registrations of PSOCQ, while there were no gender differences.

The study was approved by the Norwegian Regional Committee for Medical Research Ethics.

Measures

Pain intensity

Pain intensity was measured for the last week by numeric rating scale (NRS) from 0 (no pain) to 10 (worst pain imaginable). There was one scale for "pain during rest", and one scale for "pain during activity".

The Pain Stages of Change Questionnaire (PSOCQ)

The Pain Stages of Change Questionnaire (PSOCQ) is a measure of individuals' readiness to adopt a self-management approach to chronic pain conditions (Kerns et al., 1997). Several studies have reported substantial reliability, stability and criterion-related and discriminant validity of the measure (Biller et al., 2000; Dijkstra et al., 2001; Jensen et al., 2000; Kerns et al., 1997). This 30 item, self-report questionnaire is composed of four distinct scales that represent the four stages of change from the Transtheoretical Model of behaviour change: precontemplation (7 items), contemplation (10 items), action (6 items) and maintenance (7 items). Each item is provided with a 5 points Likert scale with scoring alternatives ranging from "strongly disagree" (1) to "strongly agree"(5). For each stage/ subscale a mean score is calculated. Item examples for the subscales are given in Table 1.

The five profiles

A profile is a presentation of all four subscale scores. For an individual patient, a profile can be drawn based on the mean scores on each of the four subscales, and this was done for each of the 184 participants. Profiles were drawn in accordance with Kerns et al, after transformation of raw scores into T-scores (Kerns et al., 2005). The individually drawn profiles were then visually compared with the five patterns of meaningful profiles identified by Kerns et al in their cluster analysis (Fig.1, from Kerns et al., 2005). Kerns also described the scoring values for each subscale in terms of means and standard-deviations from mean. It was agreed to classify based on a basically visual comparison, where the pattern of the profiles should clearly correspond to Kerns' profiles presented in Fig.1 regarding the shape and the subscale with highest score. Two of the authors (TF and AA) classified the profiles in consensus, and the easiness of classification was rated on a scale from 1 (very easy) to 5 (impossible).

Insert Fig.1 here

With her permission, we used a version of the PSOCQ translated to Norwegian by Elin Bolle Strand. The instrument was translated following a standard translation-back translation procedure (Strand et al., 2007).

Hopkins symptoms check list – 25 (HSCL-25)

Psychological distress was assessed by the Norwegian version of Hopkins Symptom Check List, 25 questions version. Validity of the instrument for assessing dimensions of psychological distress has been found in several studies (Derogatis et al., 1974; Sandanger et al., 1998). The questionnaire contains 25 questions comprising the dimensions of depression, anxiety and somatisation. The items are scored on a 4 points Likert scale ranging from not at all (1) to very much (4). The scores of the items are summed and then divided by 25. This gives a possible total score range for HSCL-25 from 1.0 to 4.0. The cut off score for HSCL - 25 is suggested to be 1.70 (Sandanger et al., 1998).

To preserve variance, we chose to include 14 patients with one missing question, mostly question number 14 loss of sexual interest. The subjects mean score in HSCL substituted occasional missing items in individual subjects (Denison et al., 2007).

Fear of movement/(re)-injury

The Tampa scale of kinesiophobia (TSK)

A 13- item questionnaire aimed at assessing fear of pain and re-injury due to movement. Each item is provided with a 4 points Likert scale with scoring alternatives ranging from "strongly disagree" (1) to "strongly agree" (4) with a possible range from 13-52 (Kori et al., 1990). The Norwegian version of the Tampa Scale of Kinesiophobia has been found to be a valid and reliable instrument, with a unidimensional underlying construct (Damsgaard et al. 2007; Haugen et al., 2008).

Arthritis Self-Efficacy Scale (ASES) (the self-efficacy for pain subscale)

Self-efficacy was assessed by the subscale of pain in the Arthritis Self-Efficacy Scale (ASES), originally developed for patients with rheumatoid arthritis (Lorig et al., 1989). The instrument has been validated for a Swedish population (Lomi and Nordholm, 1992), and the Norwegian version of the ASES self-efficacy for pain subscale has been used in several studies on back pain (Brox et al., 2005; Keller et al., 1999). The scoring options for the self-efficacy for pain

subscale were on a 6 points Likert scale ranging from “totally disagree” (0) to “totally agree” (6) with a possible raw score for each of the five questions from 0-6. The scores for the 5 items are summed and then divided by 5, giving a possible range from 0-6.

Statistics

The raw scores of each of the four subscales of PSOCQ were transformed into T-scores. Transformation into T-scores gives a mean value of 50 for the whole sample; deviation of 10 points from the mean value is one standard deviation. A cluster analysis using Ward’s method was conducted on the sample of 184 participants. Cluster analysis is a descriptive procedure designed to identify groups of patients with similar profiles or patterns of responding. A single solution with 5 possible clusters was chosen, to explore the possibility of reproducing the finding of five reliable profiles identified in Kerns’ earlier study (Kerns et al., 2005).

For comparisons of groups of data, simple cross-tabulations (Pearson’s Chi-square test) were performed. ANOVAs with follow-up LSD tests were performed with profiles as the independent variable, and the psychometric scales as the dependent values. A significance level of $\alpha = 0.05$ was adopted, and Bonferroni corrected with respect to multiple testing. The analyses were performed by SPSS for Windows version 13.0.

Results

Classification of profiles according to cluster analysis

To explore whether it was possible to reproduce the finding of the 5 profiles described by Kerns (Kerns et al., 2005), a cluster analysis with Wards method and a five-cluster solution was performed. The five patterns of profiles are shown in Table 2 and Fig.2. These clusters confirm Kerns' findings, but not all described profiles were reproduced in this sample of subjects. The two most distinct profiles are the Precontemplation profile with the highest score on the precontemplation subscale and low scores on the other three subscales seen in cluster 1 (31%); and the Participation profile with high scores on both contemplation, action and maintenance subscales and low scores on precontemplation scale identified in cluster 3 (20%) and 5 (9%). The Contemplation profile can be identified in cluster 2 (24%) and in cluster 4 (15%), although the subscale stage scores of contemplation in cluster 4 are around mean. The two other profiles Ambivalent and Noncontemplative Action could not be identified by this cluster analysis.

Insert Table 2 and Fig.2 around here

Classification of profiles according to visual inspection

Of the 184 subjects 153 (83%) were successfully visually classified into one of the five profiles described by Kerns (Fig.1). In thirty-one subjects (17%) the patterns of the subscale stage scores could not be visually identified among Kerns' described profiles, and, to illustrate this, three examples of non-fitting profiles are given in Fig.3. Profile A could resemble a Precontemplation profile, but has not the characteristic L-form, as the precontemplation and contemplation subscales are very close both with high mean T-values. Profile B's highest subscale score is on the action subscale, but it can be classified neither as Non-contemplative action profile because the contemplation subscale score is too high, nor as Participation profile or Ambivalent profile because the maintenance score is very low. The last example, profile C, has a zigzag pattern with highest scores on contemplation and maintenance, and does not fit any predescribed profile.

Insert Fig.3 here

An additional 34 (19%) subjects were rated as very difficult to place into one of the described profiles by visual inspection (score 4 on a scale from 1-5), because some subscale scores deviated from described profiles. However, when the main pattern and the highest subscale

score could be recognised and corresponded to one of the original profiles, the pattern was classified.

In Table 3 and Fig.2 the mean subscale scores in T-scores of the visually classified profiles are given. As anticipated among those with recognisable patterns they corresponded to the five profiles presented by Kerns. Profiles which could not be classified varied considerably and had scores on all subscales around the mean.

Agreement between cluster analysis and visual classification

Three main patterns of profiles were found in the cluster analysis of this material (Precontemplation, Contemplation and Participation), while all the predescribed profiles were recognised by visual identification (Fig.2). Nineteen of the 23 subjects (83%) with visually identified Precontemplation profiles were found in Cluster 1 Precontemplation. Participants with visually identified Participation profiles (n=39) were placed mainly in Cluster 3 Participation (n=21) and Cluster 5 Participation (n=10), and 25 of the 27 subjects with visually defined Contemplation profiles (93%) were found in either of the Contemplation clusters 2 (n=15) or 4 (n=10). However, altogether only 75 of the 184 subjects (41%) were classified in the same profile by visual inspection and cluster analysis. All these were placed in one of the three profiles Precontemplation, Contemplation and Participation.

Correlations between visually identified profiles, demographics, pain and psychometric characteristics

As the visual classified profiles were found to be nearly identical to Kerns, and three of these were seen in the cluster-analysis though less clearly defined, we concentrated analyses of demographic and pain on the visually identified profiles Precontemplation, Contemplation and Participation. In Table 4, demographic characteristics of the participants are related to these three profiles, and one group called "Other profiles and not classified". There were no significant differences in age or gender between these profiles. Though apparently more patients with Contemplation (41%) and Participation (41%) than with Precontemplation (26%) profiles had an educational level beyond high school (college/ university), these differences were not statistically significant ($p= 0.08$). Level of pain intensity during activity was higher in subjects with Precontemplation profiles (mean 7.8) than in subjects with Participation profiles (mean 6.7) ($p=0.04$, Bonferroni corrected significance level $\alpha < 0.02$),

while there were no statistically significant differences in reported levels of pain during rest (Table 4).

Insert Table 4 here

As shown in Table 5, two profiles appeared to have distinct and opposite psychometric characteristics. Subjects with Precontemplation profiles reported most psychological distress and least self-efficacy of pain, and also high scores on fear of movement/ (re)injury. The scores on Tampa were statistically significantly higher in subjects with Precontemplation than Contemplation and Participation profiles. The other extreme was the Participation profile group with lowest scores on emotional distress and fear of movement, and statistically significant higher self-efficacy scores than subjects with all other profiles. There were no other significant differences in self-efficacy between the visually identified profiles. The p-values given in Table 5 are statistically significant after Bonferroni correction.

The cluster- profiles Precontemplation, Contemplation and Participation showed a similar pattern. Cluster 1 Precontemplation had statistically significant higher scores on fear of movement than subjects in cluster 3 Participation ($p<0.01$), and lower scores on self-efficacy than subjects in cluster 3 and 5 Participation ($p<0.01$). The values on psychological distress were also higher in the Precontemplation cluster than in the two Participation clusters, but after Bonferroni correction this finding was not statistically significant.

Patients in each stage of change

The percentage of patients in each "stage", defined as the highest subscale or dimension score, may provide important information on the composition of the sample of patients (Dijkstra 2005), and were as follows: Precontemplation 23%, contemplation 43%, action 9% and maintenance 25%.

Discussion

The main finding in this study which compared two methods of identifying five previously described PSOCQ-profiles (Kerns et al., 2005), was that the three profiles Precontemplation, Contemplation and Participation were found both by cluster analysis and by visual inspection. As suspected not all predefined profiles appeared statistically while all five profiles could be identified visually. Although all profiles were recognised by visual inspection, about one third of the patients were difficult to classify. Only 41% of the subjects were classified in the same profile by visual inspection and cluster analysis. In accordance with earlier studies, the Precontemplation and Participation profiles were shown to have distinct and opposite psychometric characteristics, while the Contemplation profile had scores in between. Pain during activity was higher in subjects with Precontemplation profiles than in subjects with Participation profiles, but this difference was not statistically significant after Bonferroni correction.

Both the visually identified profiles and the cluster profiles were compared to Kerns' subscale profiles (Kerns et al., 2005). Theoretically the scores on the 4 subscales can be combined in many different ways. Cluster analysis is a way of classifying innumerable possible profiles into a few groups with similar patterns of responding. The results are influenced by the fact that cluster analysis contributes to a coarse categorization of individuals, and that different populations can give different cluster profiles. Accordingly, Kerns' system with 5 predefined typical clusters cannot be expected to fit all individuals in any sample, and it should not be surprising that the profiles of our cluster-analysis differed from those of Kerns (Kerns et al., 2005). A further consequence might be that visually identified patterns disagree with the results of cluster analysis. The appearance of the three profiles Precontemplation, Contemplation and Participation in this cluster analysis of a different population, could be viewed as a part confirmation of Kerns finding, and could indicate that these three profiles are the most robust because they are repeated and can be identified by both cluster analysis and visually. The psychometric results further demonstrate the characteristic differences between subjects with Precontemplation and subjects with Participation profiles, while subjects with Contemplation profiles have psychometric values in between.

As far as we know, this is the first study to report visual identification of subscale profiles of readiness to change in a population of patients with musculoskeletal pain. It is quick and easy to calculate the raw scores and means of the four subscales, and it could be meaningful in a clinical setting to view individual profiles of scores rather than to rely on the highest mean

subscale stage score. However, viewing profiles of individual scoring results could be both confusing and time consuming. One challenge was to decide how strictly we should relate our profiles to fit the presentation in Kerns' article. The authors had difficulties in discriminating profiles and keeping in mind the characteristics of all five described profiles, and among those 83% that were successfully categorised a considerable part (18%) was rated as difficult to categorise in a predefined profile or "stage". Overall, the use of the visual method, which is a method that would be practical to use clinically, was not promising. One explanation is the great individual variance in scoring patterns – in fact there are many more patterns or profiles than the five main patterns described by Kerns. It is possible that there may not, in fact, be distinct "stages" or profiles of readiness, but that every person differs along the readiness domains in ways that are unique to them, and this could explain why we were not able to classify patients. As expected, those who were successfully classified by visual inspection of profiles had subscale scores in distinct patterns that corresponded very well to Kerns' description.

In Kerns et al.'s study from 1997 women had lower precontemplation scores (Kerns et al., 1997). In this investigation there were no statistically significant differences in age or gender between the visually classified profiles, and this is in accordance with later reports (Kerns et al 2005). On the other hand, and not reported in previous studies, the level of pain intensity during activity was higher in subjects with Precontemplation profiles than in subjects with Participation profiles. However, this apparently statistically significant difference disappeared after Bonferroni correction, and the significance of this finding should be investigated in other studies. There were no differences among profiles in levels of pain during rest.

Though the sosiodemographic variables investigated did not vary between subjects with different profiles, the psychometric results showed clear differences. Subjects with Precontemplation profiles reported most psychological distress, least self-efficacy of pain and also high scores on fear of movement/ (re)injury. The Participation profile group had the lowest scores on emotional distress and fear of movement, and significantly higher self-efficacy scores than subjects with all other profiles. To perceive oneself in control of pain is assumed to vary between subjects in different stages, and the finding verifies the hypothesis that subjects with high scores on action and maintenance (the Participation profile) report more perceived control than patients in "earlier" stages (Dijkstra, 2005). Self-efficacy, defined as a person's self-beliefs in his or her ability to perform specific tasks, has been shown to be a reliable predictor of both motivation and task performance, and to influence personal goal setting (Bandura, 1977). Studies have pointed out that improvements in self-

efficacy are related to positive short and long-term outcomes of pain coping skills training and educational self-help interventions (Keefe et al., 2004). Investigators of the properties of the stages of change theory have asked for associations between the stages of change theory and self-efficacy (Biller et al., 2000; Keefe et al., 2000; Strong et al., 2002). In one study the conclusion was that the concept of self-efficacy was a better predictor of treatment outcome than the stages of change scales (Strong et al., 2002).

Fear of movement/(re)injury is one phenomenon within a theory of fear avoidance. The essence is that pain is interpreted as a sign of danger, and consequently physical activity is avoided (Brox et al., 2005; Indahl,2004; Kori et al., 1990; Pincus et al., 2006; Vlayen and Linton, 2000; Waddel et al., 1993). Regarding the concept of pain as a signal of damage and that activity should be avoided, our study supports the assumption that fear of movement is a substantial construct within PSOCQ, which varies greatly and statistically significantly between profiles (Kerns et al., 2005). The fact that degree of psychological distress was found to differ between identified visual profiles has not been reported earlier. Jensen and his colleagues reported inconsistent findings for the hypothesis that PSOCQ scale scores are associated with levels of depression and disability (Jensen et al., 2003).

Precontemplation, Contemplation and Participation represent three important profiles in the stages of change theory, clearly different concerning self-management approach to chronic pain. Clinically, these might be the three most important stages of change representing the precontemplation stage, characterized by little perceived responsibility for pain control and no interest in implementing behavioural changes, the contemplation stage, with a consideration of behavioural changes and an increasing awareness of personal responsibility for controlling pain and the participation profile with subjects with a high level of investment and involvement in self management with pain. These three profiles could correspond with three different clinical approaches with respect to motivational intervention and advice. Studies have shown that low precontemplation stage scores may predict completion of a pain management programme (Biller et al., 2000; Glenn and Burns, 2003; Kerns et al., 1997). If a person in the precontemplation stage completes a self management programme, he may profit, but not as much as individuals in a more active stage (Burns et al., 2005; Glenn and Burns, 2003; Kerns et al., 1997). A clinical implication could be to realise that it is important to identify individuals with high scores on the precontemplation scale, in order to provide them with information and education about chronic pain prior to treatment, and then to continue to motivate them during treatment (Burns et al., 2005). This view is supported by this study and by others for subjects with Precontemplation profiles (Kerns et al., 2005), but also for subjects

identified solely by high precontemplation subscale scores (Burns et al., 2005; Kerns et al 2000). Action and maintenance stage patients have attitudes consistent with the self-management orientation promoted by multidisciplinary pain programmes, and because of strong associations between these subscales, several studies have recommended a joint action-maintenance scale (Carr et al., 2006; Jensen et al., 2000; Strand et al., 2007; Strong et al., 2002). Subjects with high scores on the action scale have been found to profit from pain treatment programmes, apparently because this treatment approach supports established strategies (Burns et al., 2005). As a consequence, subjects with longstanding pain and Participation profiles should be identified and included in multidisciplinary treatment programmes (Kerns et al., 2005). Regarding contemplation stage score, some predictive ability of the scale has been demonstrated (Carr et al., 2006; Kerns et al., 2000). Pre-treatment contemplation score has been reported to be one of the parameters predicting 3-month functional outcome (Hankin and Killian, 2004). Other investigators have concluded that subjects in the contemplation stage have moderate values on psychometric scores compared to other stages (Kerns et al., 2005), a finding that was supported in our study, and it is questioned whether this scale represents an ambivalent stage (Jensen et al., 2004).

Though the number of patients is relatively high, and a broad spectrum of musculoskeletal disorders are represented, the response rate is a limitation in this study. Further, the participants included more male subjects and subjects with a higher educational level, than those not participating. A selection of participants with higher educational level, could cover a possible difference between profiles in levels of education. This study has a cross-sectional design, and future research should attempt to evaluate the predictive value of both clusters and visually identified profiles, as well as the classification method recommended in this study.

Our recommendation regarding the measure PSOCQ is to categorise as simple and meaningful as possible. The classification should be possible to accomplish prior to treatment, i.e. at or before the first consultation. Clustering by statistical cluster analysis is not feasible in a clinical setting. Visual identification with a choice between five profiles would be difficult and would still leave nearly 20% un-classified. In our opinion, subjects with longstanding pain could be classified as follows into three categories: The highest mean subscale score defines subjects as either Precontemplators or Contemplators, while a profile with low score on precontemplation and high on both action and maintenance classifies subjects into the Participation profile. This way of categorising subjects would place approximately 80% of the subjects in our sample, and leave 20% as non-classified with mixed profiles. We share

Dijkstra (2005)'s opinion in his review of the validity of the stages of change model, i.e. that further studies of validity are needed before the instrument can be applied clinically.

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Fig.1 Pain stages of change profiles as presented by Kerns et al. (2005).

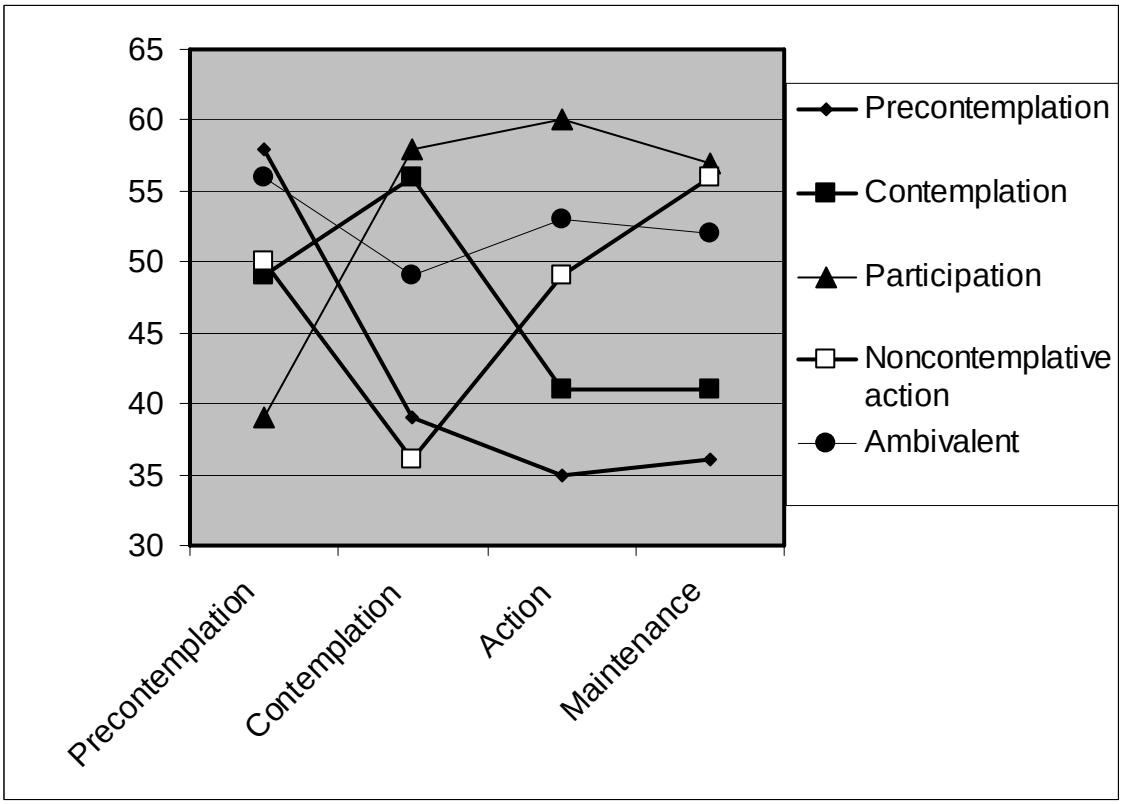
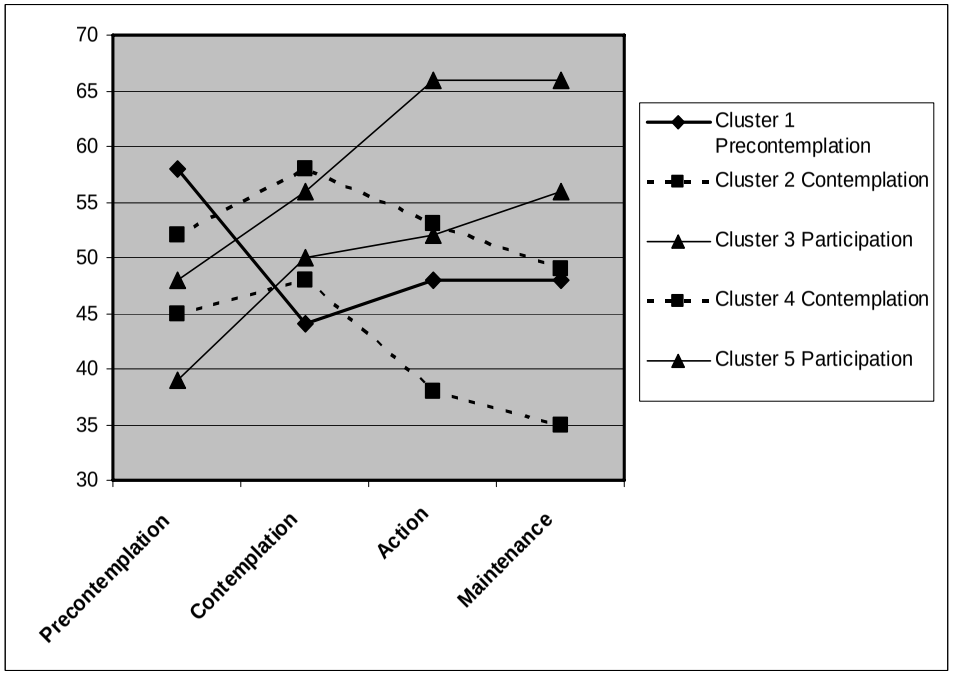


Table 1. Characteristics of the *four subscales* ("stages") of the Pain Stages of Change Questionnaire, and the *five profiles* as described by Kerns (Kerns et al., 2005). For the subscales examples of items for each of the four subscales are given.

Subscales		**Profiles**	**Characteristics of subjects**
Precontemplation	Not intending to change a specific behaviour *"All this talk about how to cope better with pain is a waste of my time".*	Precontemplation	Subjects perceive very little control over a strictly physical pain problem that requires medical attention. They believe that pain is a signal of damage that necessitates decreased activity.
Contemplation	Considering behavioural change *"I have been thinking that the way I cope with my pain could improve"*	Contemplation	Subjects believe that their pain problem is up to them to solve. They perceive a moderate level of control over their pain, and are aware that emotions affect their pain. They moderately believe that pain is a signal of damage and that activity should be avoided.
Activation	Working actively toward changing behaviour *"I am testing out some coping skills to manage my pain better."*	Participation	Subjects perceive themselves as in control of their pain. They are very active and do not believe that pain is a signal of damage that necessitates decreased activity. They do not see their pain condition as a physical problem in need of medical attention. These respondents report a high level of investment and involvement in self-management of their pain.
Maintenance	Working to maintain changes *"I have made lots of progress in coping with my pain"*	Noncontemplative Action	Subjects perceive themselves as in control of their pain. However, they do not believe that emotions influence pain. Rather, strongly believe that pain is a signal of damage and that activity should be avoided, and believe that the problem requires medical attention. These participants appear to be controlling their pain through decreased activity.
		Ambivalent	Subjects have little perception of personal responsibility for their pain, and only a moderate perception of control over their pain. They moderately believe that pain is a signal of damage that necessitates decreased activity. Yet, they are not interested in medication. They seem to be unsure of how to interpret and respond to their pain.

Fig.2 Classification of profiles according to cluster analysis by Ward's method with a single 5-cluster solution, and classification of profiles according to visual inspection.

Cluster profiles



Visually classified profiles

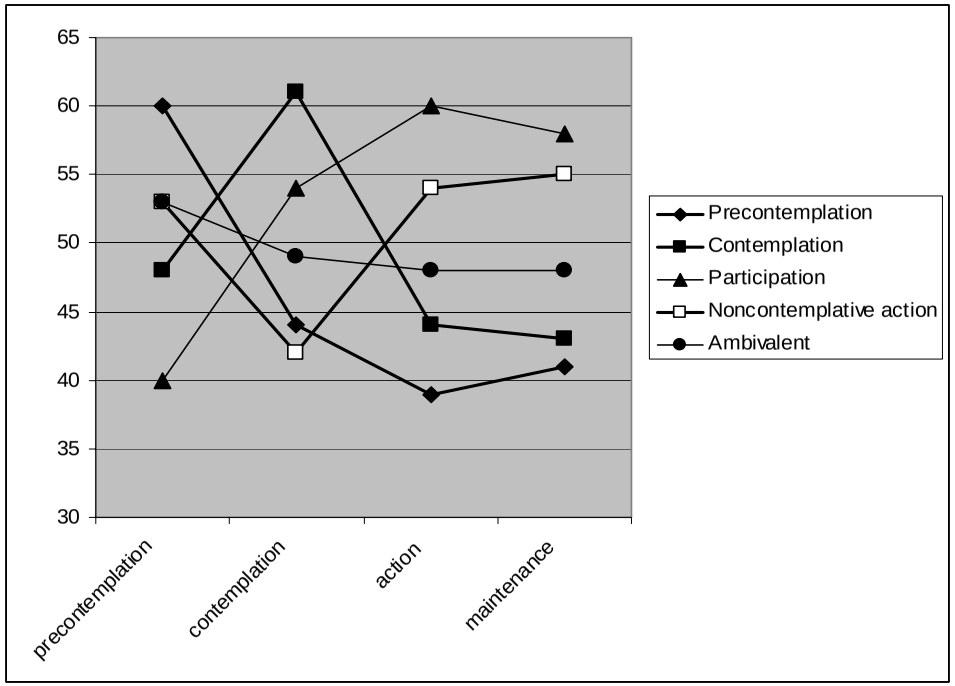


Table 2. Subscale scores by clusters for cluster analysis with Ward's method, reported in T-scores. N= 184.

Clusters		PSOCQ subscale			
	N (%)	Precontemplation Mean (SD)	Contemplation Mean (SD)	Action Mean (SD)	Maintenance Mean (SD)
1	57 (31%)	58.04 (7.76)	43.51 (8.36)	47.50 (8.80)	47.97 (6.97)
2	45 (24%)	51.79 (6.02)	57.92 (6.10)	53.02 (4.44)	48.61 (4.98)
3	37 (20%)	38.75 (6.71)	49.64 (6.45)	51.78 (9.32)	56.09 (4.94)
4	28 (15%)	45.39 (6.77)	47.77 (10.0)	38.24 (7.68)	35.46 (5.81)
5	17 (9%)	48.08 (8.79)	56.11 (10.32)	65.63 (4.05)	66.34 (4.48)
Total	184 (100%)	49.79 (9.98)	50.08 (9.77)	49.98 (10.21)	49.56 (9.93)

Table 3. Subscale scores by visually identified profiles, reported in T-scores. N= 184.

Profile	N (%)	PSOCQ subscale			
		Precontemplation Mean (SD)	Contemplation Mean (SD)	Action Mean (SD)	Maintenance Mean (SD)
Precontemplation	23 (12%)	60.08 (8.54)[1]	43.81 (10.26)	38.69 (8.56)	41.0 (5.69)
Contemplation	27 (15%)	48.23 (7.67)[2]	61.47 (7.55)	44.04 (8.24)	42.56 (8.88)
Participation	39 (21%)	40.30 (7.36)[3]	53.61 (6.91)	60.09 (7.16)	57.99 (5.97)
Noncontemplative action	29 (16%)	53.01 (7.32)[4]	41.73 (5.96)	54.28 (6.67)	54.88 (7.34)
Ambivalent	35 (19%)	53.30 (6.07)[4]	49.25 (6.62)	48.14 (6.68)	47.91 (7.93)
Not classified	31 (17%)	48.50 (10.77)	49.12 (8.92)	48.84 (9.01)	48.26 (10.84)
Total	184 (100%)	49.79 (9.98)	50.08 (9.77)	49.98 (10.21)	49.56 (9.93)

Fig.3 Three examples of not classified profiles of subscale scores of the Pain Stages of Change Questionnaire, named A, B and C.

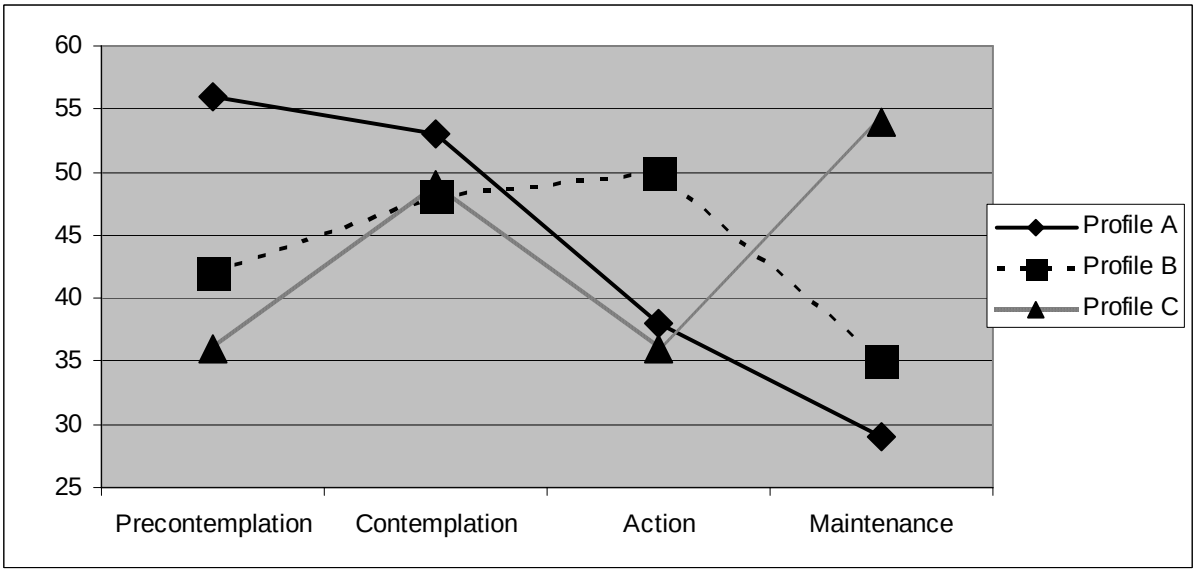


Table 4. Demographics and pain intensity in 184 participants classified into profiles based on scores of the Pain Stages of Change Questionnaire (PSOCQ). The visually identified profiles presented are the Precontemplation profile, the Contemplation profile and the Participation profile, while other profiles and those not classified are presented as one subgroup.

Demographics and pain intensity	Total	Profiles				
		Precontemplation	Contemplation	Participation	Other profiles and not classified	
		n=23	n=27	n=39	n= 95	p-values
Gender						
Men (n)	95	8	9	20	52	
Women (n)	89	15	18	19	43	ns
Age (mean SD)	41.5 (9.8)	42.1 (9.8)	41.2 (9.0)	42.4 (9.5)	41.0 (10.2)	ns
Highest Education						
Primary school (n)	34	7	2	5	20	
High school (n)	93	10	13	17	53	
College/ university (n)	55	6	11	16	22	ns
Pain intensity during rest (mean, SD) [a]	5.9 (3.7)	6.2 (2.4)	5.7 (2.0)	5.4 (2.7)	6.0	ns
Pain intensity during activity (mean, SD) [b]	7.3 (2.0)	7.8 (1.6) [b]	7.3 (1.5)	6.7 (2.3) [b]	7.5	p= 0.04 [b]

[a)] N= 181

[b)] Bonferroni corrected significance level $\alpha < 0.02$

Table 5. Scores on the Hopkins Symptom Checklist 25 (HSCL-25), the Tampa scale of kinesiophobia (TSK) and self-efficacy of pain by visually identified profiles. Percentages of subjects in each profile-group are given.

Profile	HSCL-25 N= 184 Mean (SD)	TSK N= 173 Mean (SD)	Self-efficacy N=182 Mean (SD)
Precontemplation (12%)	2.2 (0.6) [a]	31.9 (6.6) [b]	3.6 (1.5)
Contemplation (15%)	2.0 (0.4)	27.5 (6.7)	4.1 (1.6)
Participation (21%)	1.7 (0.4)	27.5 (6.6) [c]	5.3 (1.7) [d]
Noncontemplative Action (16%)	1.8 (0.4)	31.3 (6.2)	4.0 (1.7)
Ambivalent (19%)	1.9 (0.4)	33.5 (6.9)	3.7 (1.6)
Not classified (17%)	1.8 (0.5)	29.3 (10.09	4.2 (2.1)
Total (100%)	1.9 (0.5)	30.0 (7.5)	4.2 (1.8)

[a)] Significantly higher score on psychological distress in Precontemplation than in all other profiles except Contemplation profile ($p<0.01$)
[b)] Significantly higher score on Tampa scale in Precontemplation than Contemplation and Participation profile ($p<0.01$)
[c)] Significantly lower score on Tampa scale in Participation than in Precontemplation and Ambivalent profiles ($p<0.01$)
[d)] Significantly higher score on self-efficacy in Participation than in all other profiles ($p<0.01$)

Appendix

Legal and ethical approval

(These documents are written in Norwegian and are available for the commission)

1) Approval from the Norwegian Science Data Services (NSD), including changes of ending date for the project.

2) Approval from the Regional Committee for medical Research Ethics, including reports and approvals of changes.

3) The Norwegian version of informed consent

OVERSIKT OVER TIDLIGERE DOKTORGRADSAVHANDLINGER VED PHD-GRADEN I HELSEVITENSKAP DER HOVEDVEILEDER OG/ELLER BIVEILEDER HAR VÆRT ELLER ER ANSATT VED INSTITUTT FOR KLINISK MEDISIN/INSTITUTT FOR HELSE OG OMSORGSFAG, DET HELSEVITENSKAPELIGE FAKULTET, UNIVERSITETET I TROMSØ

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Hovedveileder: Professor Kenneth Asplund
Biveileder: Professor Anders Lindseth

Åshild Fause – (2007) Forpleiningen tilfredsstillende. Prisen ligesaa.
Hovedveileder: Førsteamanuensis Ingunn Elstad

Gunn Kristin Øberg – (2008) Fysioterapi til for tidlig fødte barn. Om sensitivitet, samhandling og bevegelse.
Hovedveileder: Professor Eline Thornquist

Cathrine Arntzen – (2008) ”Jeg får ikke hendene til å gjøre det de skal gjøre”
Å leve med apraksi etter hjerneslag.
Hovedveileder: Førsteamanuensis Ingunn Elstad

Aud-Mari Sohini Fjelltun (2009) Waiting for nursing home placement:
A study of the life situation of frail elderly and their carers.
Hovedveileder. Førsteamanuensis Ketil Normann
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Gudrun Nilsen (2009) Smerter under Nordlyset. Den vanlige lidelsen. Det uvanlige livet.
Hovedveileder: Professor Ingunn Elstad

Erratalist e

Levert 26 01 10

2) Side 23: Table 1 Education: Kolonne 2 (paper 2) er flyttet et hakk ned for å harmonere med utdanningskategoriene.

3) Side 33: Manglende kapittelnummer lagt til: 3.3 ”Staying Active despite pain..”

4) Side 39: Feil kapittelnumme . Endret fra 4.2.3 til 4.2.1 : ”Perspectives from the qualitative analyses”.

5) Side 33, linje 2 og 3: Lagt til: The likelihood of experiencing pain during general activity was also positively associated with a large pain distribution (while the likelihood of pain during exercise was negatively associated wit a higher sense of pain self efficacy.

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