Chronic pain and kinesiophobia among older adults. Prevalence, characteristics and impact on physical activity.

Larsson, Caroline

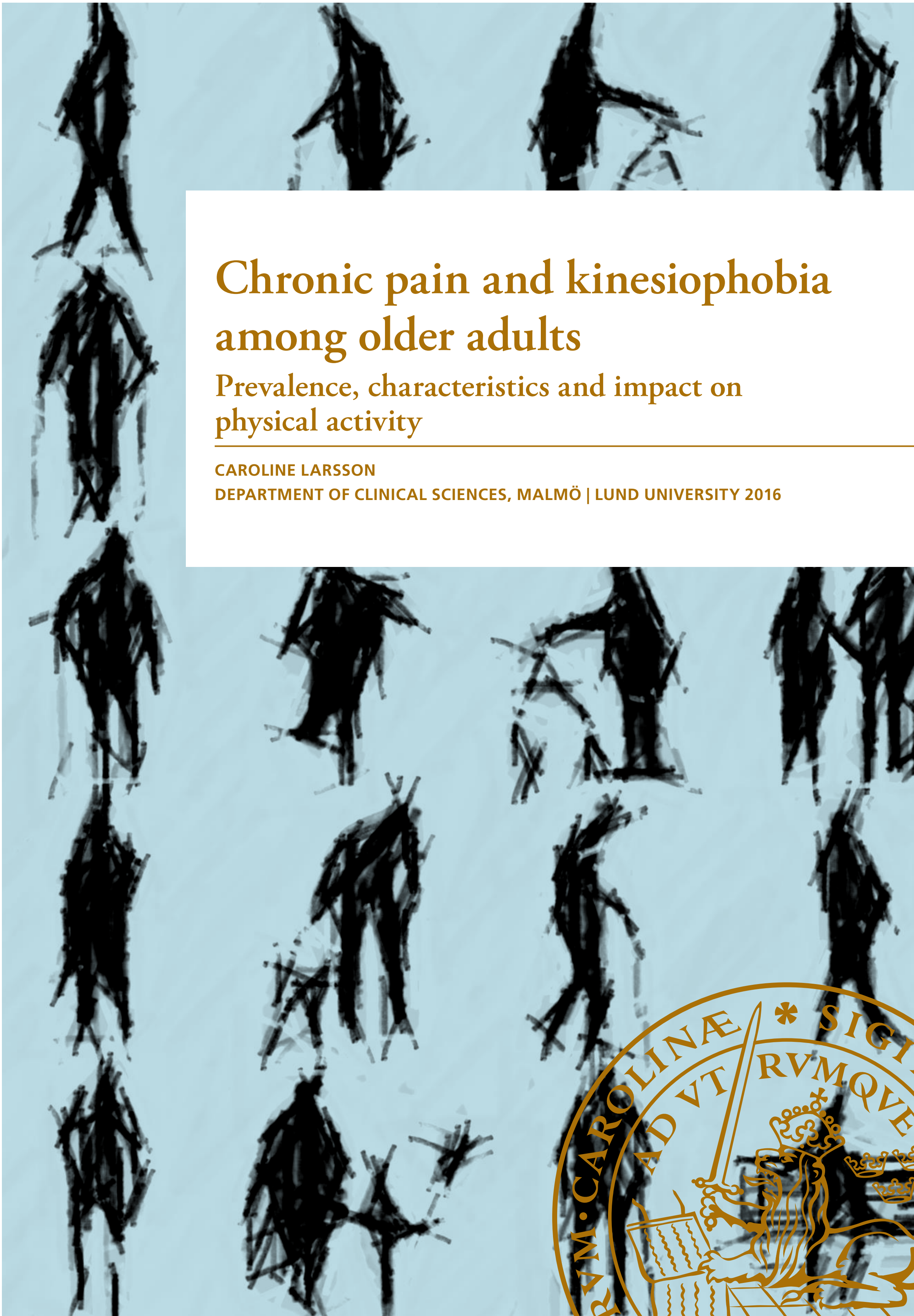
2016

Document Version:
Publisher's PDF, also known as Version of record

Link to publication

Citation for published version (APA):
Larsson, C. (2016). *Chronic pain and kinesiophobia among older adults. Prevalence, characteristics and impact on physical activity.* [Doctoral Thesis (compilation), Faculty of Medicine]. Lund University: Faculty of Medicine.

Total number of authors:
1



Chronic pain and kinesiophobia among older adults

Prevalence, characteristics and impact on physical activity

CAROLINE LARSSON
DEPARTMENT OF CLINICAL SCIENCES, MALMÖ | LUND UNIVERSITY 2016

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Caroline Larsson

LUND UNIVERSITY

DOCTORAL DISSERTATION
by due permission of the Faculty of Medicine, Lund University, Sweden.
To be defended at Aulan, Clinical Research Centre,
Jan Waldenströms gata 35, Malmö
15 September 2016 at 9.00 am

Faculty opponent
Professor Stefan Bergman
University of Gothenburg

Organization
LUND UNIVERSITY

Center for Primary Health Care Research
Department of Clinical Sciences, Malmö
Faculty of Medicine

Author(s): Caroline Larson

Document name
DOCTORIAL DISSERTATION

Date of issue
15 September 2016

Sponsoring organization

Title and subtitle: Chronic pain and kinesiophobia among older adults – Prevalence, characteristics and impact on physical activity

Abstract

Background: Chronic pain is common in older adults, yet little is known of its development in old age. Although fear-avoidance beliefs in chronic pain have been explored in younger adults, the relationship between chronic pain, kinesiophobia and physical activity levels has not been investigated in older adults.

Objectives: The overall aim was to explore prevalence, development and related factors of chronic pain and kinesiophobia in older adults with a focus on psychosocial and pain-related factors and their impact on physical activity among older adults.

Methods: The study had a longitudinal design and data were obtained through posted surveys and collected at baseline and after 12 and 24 months during 2011–2013. Participants (N=2000) were selected through simple randomization of the Swedish register of inhabitants using the whole Swedish population aged 65+, as sampling frame. A total of 1141 older adults were included at baseline (aged 65–103 years). Prevalence, incidence rate and cumulative incidence of chronic pain over 2 years in different age strata were estimated. To estimate associations for demographic, psychosocial and pain-related variables as functions of chronic pain (persistence and onset), kinesiophobia and physical activity linear/logistic regression analysis were performed.

Results: In paper I, chronic pain was reported by 38.5% of the participants, more common among females and those over 85 years. The incidence was estimated at 5.4%. Being female, having lower BMI, high intensity/severity, long duration and multiple locations of pain were able to predict persistence of chronic pain. Paper II showed that TSK-11 had acceptable construct validity, factor structure and test-retest reliability. In Papers III–IV generally low levels of kinesiophobia were found among those with chronic pain, except among frailer and older adults living in care homes. Despite this, it was found that kinesiophobia was independently associated with levels of physical activity and significantly lower levels of physical activity among those with chronic pain.

Conclusions: Even though chronic pain was often highly prevalent and persistent, both onset and recovery occurred over time. The findings highlight the importance of early pain management in prevention of future pain among older adults. It must also be considered that older adults with chronic pain are at higher risk of functional decline and additional chronic diseases, due to significantly lower levels of physical activity compared to older without chronic pain. Kinesiophobia among older adults can be captured by the TSK-11 and plays an important role in predicting future physical activity levels and is hence important to consider. Potential interventions against kinesiophobia among older adults should aim to decrease pain intensity and strengthen health beliefs.

Key words: Chronic pain , kinesiophobia, older adults, physical activity, epidemiology, psychometric evaluation

Classification system and/or index terms (if any)

Supplementary bibliographical information

Language English

ISSN and key title
1652-8220, Lund University, Faculty of Medicine Doctoral Dissertation Series 2016:78

ISBN 978-91-7619-304-4

Recipient's notes

Number of pages:

Price

Security classification

Signature

Date 2016-08-10

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ISBN 978-91-7619-304-4
ISSN 1652-8220

Printed in Sweden by Media-Tryck, Lund University
Lund 2016

Att bli gammal

Till att bli gammal är inte som att vara
ung, i bland så känns det ganska tungt.

Allt är häng och torrt är skinnet,
trist i sinnet och klent är minnet.

Mun är full av köpta tänder,
bruna fläckar syns på händer.

Själv brukar ja grina och tankarna sina,
hjärncellerna blir som förvridna.

Reumatismen plågar en i låret,
rakt å stripigt hänger håret.

Och slut är det på erotiken,
ingen liten vän i viken.

Ögonlocken är som gardiner,
blodådran som serpentiner.

Men åren bara går år från år.

Det går inte att fatta att det är sant,
att man blivit en gammal tant.

Skriven av Ulla Persson i Börtnan

Contents

Abstract

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Original papers

I. **Larsson C**, Hansson EE, Sundquist K and Jakobsson U. Prevalence, incidence and risk factors of chronic pain in older adults: a longitudinal cohort study (Scandinavian Journal of Rheumatology. Accepted 26 July 2016).

II. **Larsson C**, Hansson EE, Sundquist K and Jakobsson U. Psychometric properties of the Tampa Scale of Kinesiophobia (TSK-11) among older people with chronic pain. Physiotherapy Theory and Practice 2014 Aug; 30(6):421–8.

III. **Larsson C**, Hansson EE, Sundquist K and Jakobsson U. Poor self-rated health and high pain intensity contributes to high kinesiophobia in community-dwelling older adults with chronic pain. BMC Geriatrics. Published online 7 July 2016 DOI: 10.1186/s12877-016-0302-6.

IV. **Larsson C**, Hansson EE, Sundquist K and Jakobsson U. Impact of pain characteristics and fear-avoidance beliefs on physical activity levels among older adults with chronic pain: A population-based, longitudinal study. BMC Geriatrics. Published online 24 February 2016 DOI: 10.1186/s12877-016-0224-3.

Abbreviations and definitions

ADL:	Activities of Daily Living
BMI:	Body Mass Index
CI:	Confidence Interval
GSE:	General Self-Efficacy scale
IASP:	International Association of Pain
ICC:	Intra-Class Correlation
IPAQ:	International Physical Activity Questionnaire
MPI:	Multidimensional Pain Inventory
OR:	Odds Ratio
SF-12:	Short-Form Health Survey
SPAR:	Swedish Personal Address Register
SPSS:	Statistical Package for the Social Sciences
TSK-11:	Tampa Scale of Kinesiophobia (11-item version)
WHO:	World Health Organization

OLDER ADULTS	In this thesis, the age of 65 years was chosen to define older adults, based upon the age of retirement in Sweden
CHRONIC PAIN	Pain without apparent biological value that has persisted beyond the normal tissue healing time (usually taken to be 3 months)
KINESIOPHOBIA	An excessive, irrational, and debilitating fear of physical movement and activity resulting from a feeling of vulnerability to painful injury or re-injury
PHYSICAL ACTIVITY	Any bodily movement produced by skeletal muscles that requires energy expenditure

Introduction

With increasing age, older adults are undeniably at increased risk of developing multiple long-term health conditions that cause pain. In accordance, previous epidemiological studies show that many older adults are living with untreated or partially treated pain [1-4]. Untreated or undertreated chronic pain may affect many aspects of life in old age, and older adults often report symptoms such as sleep problems, depression, functional decline and low quality of life in relation to chronic pain [1, 5-7]. The current change in age structure of our society means that in the planning of future health and medical care, more account must be taken of the needs of an ageing population. This places high demands on knowledge about chronic pain causality in older populations, a knowledge that is deficient in health care today. For example; estimates for the oldest old are by and large missing and few longitudinal studies report on risk factors in older populations.

Kinesiophobia (fear of movement due to pain) is identified as contributing to the persistence of chronic pain and proposed to be an important link between pain and disability in general populations [8]. However, studies on the occurrence and development of kinesiophobia among older adults are lacking and no measures to capture the phenomenon have been validated for older adults. Hence little is known about how kinesiophobia interferes with chronic pain in old age. Such knowledge is important since kinesiophobia, besides perpetuating the pain, may also lead to decreased levels of physical activity, which further increases the risk of disability, morbidity and even mortality among older adults [9-11].

If pain experience did not differ between older and younger people, it would be possible to generalize the knowledge from younger populations to older adults. However, previous evidence suggests that age-related changes affect the pain experience and that some factors related to pain may operate in a somewhat different manner across age groups. This would mean that the trajectories to chronic pain might differ between older and younger people and that intervention should be targeted differently based on age. This supports the need for further investigations on the aetiology of chronic pain among older adults.

To increase the knowledge and to increase the generalizability of the results, chronic pain and related factors must be investigated longitudinally and broadly, i.e. regardless of specific cause or pain locations in the body. Such knowledge might contribute to field of research with an additional piece of the puzzle, by increasing the understanding of the development of chronic pain and its consequences among older adults, while also enabling an improved basis for prevention and intervention, as well as improving general health and quality of life and decreasing mortality in the elderly population.

Background

An ageing population

The process of becoming older – *Ageing* – consists of complex physical, psychological and social changes accumulating over time [12]. It is an individual process and differences may be due to primary factors such as genetic factors, but also to secondary factors such as environmental effects, lifestyle and the influence of disease or illness [12]. Biological ageing is related to a decrease in function and capacity in the organs of the body, followed by a gradual decline in physical and mental capacity, a growing risk of disease and mortality [13]. Psychological ageing refers to the changes that occur in an individual's personality and mental functioning, such as cognition, intelligence, memory and learning ability. Social ageing refers to social and cultural expectations placed on older adults and as well as older individuals' position in society [13].

Due to the individual process of ageing, the number of years lived is not a sufficient measure of the extent of ageing. Nor is there any agreement about what chronological age defines "old age". However, in the developed world, the age of retirement is commonly used to define old age, often the age of 65. The age of 60 is also used by both the World Health Organization and the United Nations when referring to the older population [14]. In research contexts, distinctions are often made between groups of older people, one example is "young old" for people aged 65–85 years old, and "old-old" referring to people aged 85 or older and the "very old" for those 90 and older [14]. In this thesis we have chosen the age of 65 years to define older adults, based upon the age of retirement in Sweden.

Population ageing refers to the progressive increase in the actual numbers and proportion of older people within total populations [13]. Due to improved life conditions, decline in infant and premature mortality, improvements in housing, nutrition, medical innovations and sanitation, life expectancy has dramatically risen [15]. In recent demographic analyses the numbers people aged 65+ (relative to those aged 15-64) are projected to increase from 27.8% to 50.1% by 2060 [16] The numbers of people aged 80+ will be the fastest-growing age group and are expected to triple by 2050 [15]. The Swedish population is also ageing rapidly. Over the last 10 years the population of 65 years or older has risen by one per cent.

Today 19.8% or 1.9 million of Sweden's population are 65 years of age or older [17]. In 2060 this group is predicted to have grown to reach 25% of Sweden's total population [17]. The proportion of people aged 100 years or more is the fastest-growing age group in Sweden. In 1970 there were 127 residents in Sweden who were over 100 years old and in 2014 there were 1953, a number predicted to continue to increase to 9000 in 2060 [17]. This change in the age structure of our society means that in the planning of future health care and social services, more account must be taken of the need of the ageing population. With increasing age older adults are undeniably at increased risk of developing multiple long-term health conditions with painful sequelae [18]. It should however be noted that age is never equal to disease. Age should instead be seen as a proxy for potential causal biopsychosocial and lifestyle factors [19].

Pain

Pain is the alarm system meant to warn us that something is threatening to hurt our body. The International Association for the Study of Pain, IASP, defines pain as *"an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage"* [20]. This tells us that, besides being both a sensory and emotional experience, pain is also highly subjective.

Somewhat simplistically, one could say that this way of viewing pain originates from the late 1960s, with the introduction of the Gate Theory, presented by the psychologist Ronald Melzack and the anatomist Patrick Wall [21]. The theory proposed that nerve signals that transport information about injured tissue or tissue threatened with damage (nociception), did not go directly to the brain but was modulated in the spinal cord of both signals from tissue (signals including touch nerves) and by signals from the brain (descending inhibitory signals). This view could in a way be said to be a paradigm shift, as last century's view of pain had been almost completely dominated by a biomedical and dualistic approach to pain, in which the body and mind were viewed as functioning separately and independently [22].

Ronald Melzack developed these thoughts further into the Neuromatrix theory of pain (figure 1)[23], which today is a widely accepted model explaining pain. The model puts much more emphasis on the brain's role in the pain experience and proposes that the experience is not a passive registration of tissue damage in the brain, but that the brain itself actively generates the pain experience [23]. This happens through a network of neurons called the body-self neuromatrix, which integrates sensory-discriminatory, motivational-affective, and cognitive-evaluative components. While the “sensory-discriminative dimension” of pain handles information such as intensity, location and duration of the pain (it hurts), the “affective dimension” relates to emotional and behavioural responses (it is uncomfortable) and the “cognitive-evaluative dimension” of pain represents the consequences pain has on thoughts and acts [24]. This bio-psycho-social view of chronic pain concludes that pain is a multidimensional experience which is filtered through a wide range of psychological and socioeconomic factors such as genetics, prior learning history, current psychological and sociocultural influences [22]. The interrelationship between biological changes, psychological status and social context must hence be considered in order to fully understand an individual’s experience of pain.

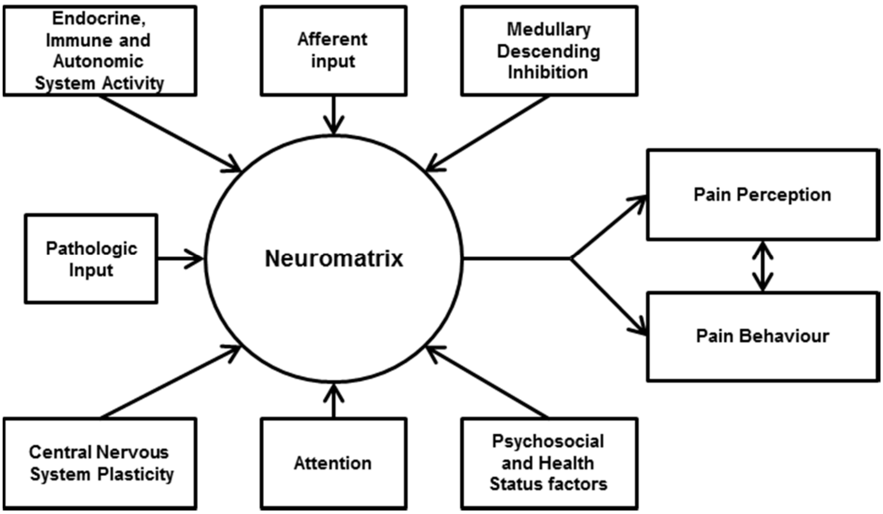


Figure 1
The neuromatrix as described by Melzack. Reprinted from Melzack R. From the gate to the neuromatrix. Pain 1999;6 Suppl:S121-6,with permission from Wolters Kluwer Health,Inc

Chronic pain

Pain can be categorized in different subgroups. A commonly used way of categorizing pain is by its duration: acute, sub-acute and chronic. The onset of acute pain is often some kind of trauma or injury, the tissue has been hurt or has been at risk of injury. Acute pain has a short duration and the sensory-discriminative dimension (i.e. intensity, location and duration) is the dominating experience [25]. When pain continues for a longer time it is considered to be persistent or chronic. The following definitions are frequently used when chronic pain is described in the literature. *"Chronic pain persists after all possible healing has occurred or, at least, long after pain can serve any useful function"* [26] or as the International Association for the Study of Pain (IASP) which defines chronic pain as *"pain without apparent biological value that has persisted beyond the normal tissue healing time (usually taken to be 3 months)"* [20]. Three months is also the time interval used for defining chronic pain in this thesis.

The bio-physiological explanation behind chronic pain is that even after short-term acute pain stimulation, changes at all levels occur and transmission of pain signals is moderated on both peripheral and spinal level as well as in our brain. At peripheral level, the normal threshold is reduced (peripheral sensitization) because the tissue damage secretes inflammatory substances (prostaglandins and cytokines) that bind to the pain receptors [24]. This contributes to an increased responsiveness to mechanical, chemical and thermal stimuli and makes pain fibres more easily activated (primary hyperalgesia) [24]. The nociceptive inflows also have an impact on spinal cord level, leading to increased responsiveness to secondary neurons as well as to surrounding neurons (central sensitization). When surrounding neurons are activated it contributes to perceiving the pain as coming from a larger area (secondary hyperalgesia/wind-up). At brain level it has been seen that different areas of the brain are activated when the pain persists. Instead of frontal cortex, deeper structures of the brain are activated to a greater degree, which in turn affects a variety of other functions, e.g. rest/sleep, hormone secretion and memory/learning. Chronic pain is thus not just an acute pain extended in time. The changes above are some of the bio-physiological explanations behind chronic pain [24], but when pain becomes chronic an increasing role is attributed to psychosocial factors.

Fear-avoidance beliefs in chronic pain

A concept that has contributed to the understanding of psychosocial factors in chronic pain is the concept of fear and avoidance. Letham with colleagues introduced the "the fear-avoidance model of exaggerated pain perception" [27]. He proposed that there are two extreme opposing coping responses to fear, namely confrontation and avoidance. Simplified, confrontation leads to reduction of fear over time and avoidance leads to maintenance and worsening of fear and at worst to a phobic state. Avoidance is seen to have two components: "avoidance of the pain experience", which is seen as the cognitive component and "avoidance of activities", which is seen as the behavioural component. Both types of avoidance lead to minimization or total avoidance of physical and social activities and hence a range of both physical and psychological consequences [27]. Avoidance of activity is a natural reaction, which normally allows an injury to heal, but among chronic pain patients, avoidance behaviour is found to persist longer than it takes for the actual injury to heal. The reason for this is suggested to be short-term effects of reduced suffering, and beliefs that further exposure to certain stimuli will increase pain and suffering [28].

Vlaeyen and colleagues developed these thoughts further in "the cognitive-behavioural fear-avoidance model", describing how fear of movement/(re)injury contributes to the development of chronic pain (figure 2) [28]. He argues that a painful experience (exaggerated during movement), when interpreted as threatening, can generate catastrophizing beliefs that physical activity will result in more pain and re-injury. Those who are catastrophizing are more likely to be fearful, which can lead to increased avoidance behaviour and in the long run cause disability, disuse and depression. Based on his model, Vlaeyen introduced the concept of "fear of movement" using the definition "a specific fear of movement and physical activity that is wrongfully assumed to cause re-injury [28]. Fear-avoidance beliefs may be particularly determinant in the elderly population.

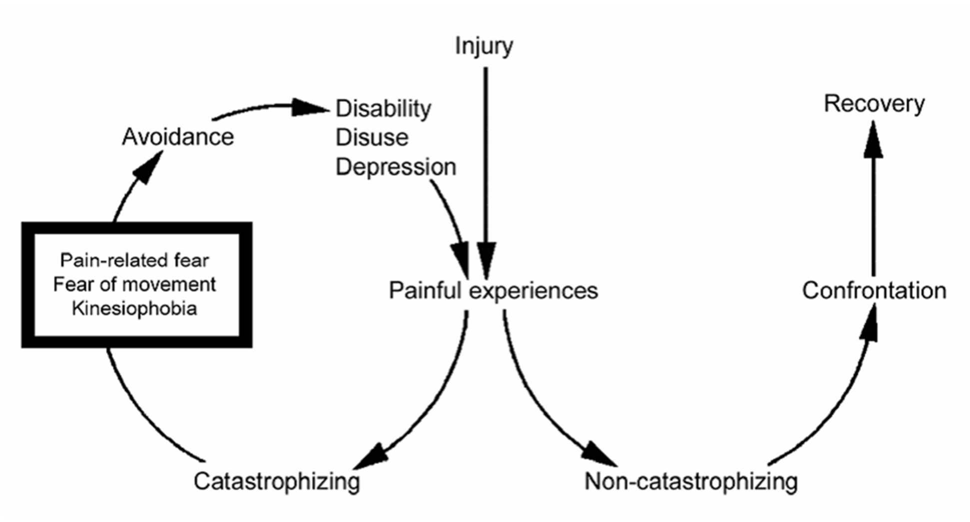


Figure 2.
A cognitive-behavioural model of fear of movement/ re(injury) by Vlaeyen et al. Vlaeyen et al., Fear of movement/(re)injury in chronic low back pain and its relation to behaioural performance. Pain 1995:62(3)363-372). Reprinted from Mari Lundberg thesis [29], with permission.

Kinesiophobia

In its more excessive state this fear of movement can be referred to as kinesiophobia. The concept of kinesiophobia was introduced by Kori and colleagues, defined "as an excessive, irrational, and debilitating fear of physical movement and activity resulting from a feeling of vulnerability to painful injury or re-injury" [30]. There is confusion between the concepts, and in the literature pain-related fear/fear of movement and kinesiophobia are often used synonymously. Some authors differentiate between kinesiophobia and fear of movement by describing kinesiophobia as a stronger concept and with a phobic nature [29]. It has been discussed that what differentiates the concept of phobia from fear is that a phobia is a non-proportionate fear that cannot be explained, and with a reaction to it that is out of volitional control. Subsequently, people who experience phobia change their behaviour and life to avoid the threatening situation even though they might be aware that the threat is exaggerated. Anxiety that is found to be the primary affective component of phobia is highly correlated to kinesiophobia [31]. Fear, in turn, can in many cases be a natural reaction to a realistic threat. However, the consequences of fear avoidance and kinesiophobia are closely related, e.g. catastrophic cognition, increased pain intensity, disability, disuse and depression. In this thesis, the concept of fear of movement will hence be used in parallel with kinesiophobia. Both these concepts are important to examine in the elderly population.

Chronic pain in old age

Age-related differences in pain experience

Age-related physiological changes occur in several structures known to be involved in pain processing [32], and could hence contribute to possibly age-related differences in pain perception. Primarily based on laboratory studies, increases in pain threshold (the lowest value at which the person reports that the stimulation feels painful), and a decrease in pain tolerance (the lowest stimulation level at which the subject withdraws or asks to have the stimulation stopped), increased vulnerability to neuropathic pain and decreased vulnerability to acute pain related to visceral pathology have been reported to be effects of age-related changes in the processing of pain [33]. These changes may be due to a decrease of myelinated nerve fibres at peripheral level, loss of brain volume (mainly in the hippocampus and prefrontal cortex) and slower cognitive processing [32]. In addition, research has also shown that older adults may be less tolerant to pain once it begins and that they experience pain for a longer time after tissue injury [32]. This may be due to reduced plasticity and that the function in the descending inhibitory pathways in the brainstem and spinal cord declines with age, resulting in reduced ability to modulate pain. However, as previously mentioned, these findings basically derive from laboratory studies and in reality it is probably not so simple that the prevalence of pain either increases or decreases with age, but instead varies between type of pain and between individuals, consistent with the bio-psychosocial model [34].

Epidemiology of chronic pain among older adults

The prevalence of chronic pain among older adults varies considerably between previous epidemiological studies, ranging between 27 and 86% [1-4], where some studies indicate an increased prevalence with age [4, 5, 35, 36]. Other studies indicate a flattened or declining prevalence [1, 37, 38]. Despite the generally high prevalence of chronic pain and the high vulnerability that comes with age, pain is often undertreated or not recognized by health professionals among both community-dwelling and institutionalized older adults [39-42]. Also in Swedish samples undertreatment of pain does seem to be a significant problem. In a study from 2006 in a geriatric care setting (n=2.724, mean age 83.3), 27.9% of those suffering from pain did not received any analgesics as regular medication although the staff often believed that the resident was receiving treatment [43].

There are various causes behind chronic pain: an acute injury as well as a pain without any certain onset or measurable causality. Frequently reported causes of chronic pain are osteoarthritis, various forms of arthritis, arthralgia, back pain, herpes zoster and cancer [44, 45]. An increase with age has also been seen to be dependent on pain diagnoses. For example, more generalized pain diagnoses such as fibromyalgia show an increase with age [36], whereas more specific diagnoses such as migraines, chest pain, low back pain and stomach pain have shown a decreased prevalence with age [38]. In many cases, however, it is not clear what causes the pain and studies have reported that as many as 42% have not received any medical diagnosis or do not know the reason why they have pain [46]. Commonly reported locations for pain among older adults are: bones, joints and back, primarily lower back [37, 46]. It is also common that there is more than one site of pain. In a study from 2011, 80% of the respondents reported more than two sites of pain [46]. Multiple sites of pain have also been found to be independently associated with increased functional limitations and greater disability [1, 47] as well as with increased psychological distress [48].

In addition to multiple pain locations, the duration of pain must also be considered. Older adults with chronic pain have often had pain for an extended period of time, but whether and to what extent older adults also develop chronic pain in old age has been sparsely studied. Some estimates of incidence can be made from longitudinal studies including both younger and older adults, and vary between 2.1% and 6.4% [49, 50]. In another Swedish longitudinal study, 34% of those not reporting pain at baseline reported pain 12 years later [51]. However, although these studies have included older adults (+65 years), development of chronic pain has only been reported for the whole samples. Some longitudinal studies have studied the development of chronic pain with respect to older adults in particular, but these studies have been either pain-site-specific [4, 52], small [53], or excluding the oldest old [54]. Hence, more generalizable incidence estimates among older adults as well as prevalence rates among the oldest age groups (85+) are largely missing, which means that the knowledge of chronic pain development among the older adults, and especially among the oldest old, is still inconclusive.

Chronic pain, associated factors and some impacts on life in old age

Untreated chronic pain can have a great impact on an individual's physical and psychological health in all ages and is established to be a major risk factor for disability, depression and decreased quality of life in old ages [1, 7]. Anxiety, mood disturbances and depression are often reported among older adults [55, 56] and a majority of older adults diagnosed with depression also report chronic pain [56, 57]. The impact of depression in old age can be severe and includes outcomes such as functional decline, disability, social isolation and suicidal thoughts [58]. However, not all older adults develop depression from chronic pain. In previous studies it has been estimated that approximately one in four are at a clinically relevant risk of depression [45]. Who develops depression from chronic pain is not entirely clear, but previous studies have shown that older adults with high pain intensity suffer from depression to a higher extent than older adults who report low pain intensity [59]. Similarly, in a large survey of community-dwelling older adults, the odds for depressive symptoms increased from 27.9–84.2% when disabling low back pain increased from little of the time to all of the time [57]. Not knowing the cause of the pain has also been shown to be related to the presence of mood disorders [60] and may lead to the elderly themselves being strengthened in their belief that pain belongs to the normal ageing process, which complicates the prospects for good care and treatment [61].

Sleep disturbances are another commonly reported consequence of chronic pain [62, 63], and this also seems to be the case among older adults [64]. Problems with sleep include difficulties falling asleep, maintaining sleep as well as sleeping too much. Multiple sites of chronic pain are found to double the risk of sleep problems [65]. Besides being a common consequence of chronic pain, sleep disturbances are also found to contribute to poor pain modulation and may hence also be a risk factor for the aggravation of chronic pain [66]. Sleep disturbances may also lead to fatigue [67, 68], which is relevant in relation to chronic pain as fatigue is found to be strongly related both to disability and to physical activity [68-70]. In a study among older women with knee and hip osteoarthritis (n=60, aged +55 years) pain was found to be positively associated with physical activity only in the presence of fatigue [71]. Fatigue may hence play a mediating role between chronic pain and physical activity.

Chronic pain may also lead to disability [1, 5, 6]. Pain-related disability can be seen as an umbrella concept, which includes a variety of domains such as self-care behaviours, physical, occupational and social functioning [72]. In a longitudinal cohort study among older adults (n=765, aged 64–97 years) distribution, severity and interference of chronic musculoskeletal pain were found strongly associated with an increased risk of developing mobility and ADL difficulty, and individuals with chronic pain at baseline showed a larger decline in mobility performance over 18 months [73]. There is also accumulating evidence, mostly from cross-sectional studies, that mobility difficulties, such as balance and gait impairments, are related to chronic pain in old age [1, 5, 6]. For example, in a study using in-person interviews among older adults in the United States, self-reported inability to walk 3 blocks was found to be 72% higher among those with chronic pain [1]. The relation between pain and disability also seems to be dependent on the number of painful sites. In a study in a religious setting among non-disabled community-dwelling older adults (*n*=759, mean age 73.9), the risk of ADL disability was found to increase by 20% (HR=1.20, 95% CI 1.11, 1.31) for each painful area reported even after controlling for a wide range of confounders [47]. In the same setting, musculoskeletal pain was found to be associated with greater odds for incident mobility disability (OR=1.38, 95% CI=1.11–1.73) and musculoskeletal pain in three or more sites further increased the risk of mobility disability (OR=1.80, 95% CI=1.31–2.47) [74]. Among older adults in retirement communities and home care the risk of disability has also been found to increase with pain severity and with the number of painful sites [75].

Chronic pain also has a large impact on society. For example, pain is found to be related to health care usage and health care costs [5, 76, 77]. In a recent study from Sweden it was found that consumed health resources increased with the severity of chronic pain. The cost of chronic pain for society with regard to health care, drugs, municipal services and informal care was estimated at amounts of more than 1 billion EUR for the average person over 65 years. This can be compared to 9.2 billion that was estimated to be the entire cost of the same age group [77]. To sum up, it can be concluded that chronic pain in old age is often accompanied by a wide range of symptoms that can be both triggered and aggravated by pain and that many factors are in fact interrelated. It also seems that chronic pain leads to progressive problems and deteriorating function over time. The many complex relationships complicate assessment and treatment of pain among older adults. Altogether this shows that chronic pain has a large impact on many aspects of the daily life of older adults, as well as for society, and it urgently calls for increased knowledge and improved management of chronic pain among older adults.

Predictors of chronic pain

To identify individuals at risk of chronic pain and thereby enable well-targeted interventions, a good knowledge of risk factors for the development and persistence of chronic pain are essential. Among the general population, risk factors for chronic pain are relatively well established and include: younger age, female gender, lower socioeconomic status, pain itself (i.e., increased pain severity and number of pain sites), psychological factors (e.g., anxiety, depression and catastrophic beliefs about pain) as well as co-morbidity, genetic factors and heritability [78]. However, for psychological factors (e.g., anxiety, depression and catastrophic beliefs about pain) the temporal relationship is still not fully understood [78]. Most of the factors related to chronic pain among older adults previously described above originate from cross-sectional designs and do not have the possibility to provide any information on temporal relationship among older adults. A few prospective studies have been conducted. Docking et al. (2011) examined risk factors for chronic back pain in older people with back problems (n=458, mean age; 83.0, range; 77.4–100.6 years) and found that poor self-rated health, depressive symptoms, increased use of health or social services, and previous episodes of back problems predicted chronic back pain at follow-up 3.5 years later [4]. Leung et al. found that lower education level, living alone and poorer self-rated health predicted chronic pain onset two years later among community-dwelling older adults in Singapore (n=3103 mean age=69.4) [79]. In a registered based study from the Netherlands it was found that older men and women (n=1271, aged 55–85 at baseline) with high BMI had at least a twofold risk of incidences of pain after 6 years, after adjustment for age, education, depression, smoking, physical activity and chronic diseases [54]. In contrast, Benyon et al. found that lower scores of catastrophizing at baseline were predictive of higher pain at follow-up 6 months later in patients aged 50+ years with musculoskeletal pain [80]. Nevertheless, the specific contexts of previous findings (i.e. back pain) make them difficult to generalize to older adults without a specific cause or site of pain. As multiple pain locations are common among older people and seem to aggravate the impact of pain in many respects, a search for general (non-diagnosis or site-specific) predictors of pain seems especially important.

Kinesiophobia in old age

There are indications that some psychosocial factors may operate in a somewhat different manner across age groups. For example, it has been shown in cross-sectional studies that catastrophizing plays a stronger role in pain-related disability among the elderly compared with younger individuals [81, 82]. However, the prevalence of kinesiophobia and its interrelationship to the constructs postulated in the fear-avoidance model have been sparsely investigated among older adults. In one study, structural equation modelling was used to validate the predictive relationship between different factors within the fear-avoidance model (i.e. catastrophizing, pain-related fear/kinesiophobia, depression, perceived disability and pain intensity) over different age groups [82]. It was found that respondents in the oldest age group (range 55–82 years) presented with low kinesiophobia (measured with the Tampa Scale for Kinesiophobia) compared to the middle-aged (range 41–54 years). However, it was also seen in the oldest age group that kinesiophobia had a stronger mediating role between pain catastrophizing to depression and disability compared to the younger subjects. Kinesiophobia has also been found to be associated with disability in cross-sectional studies among community-dwelling older adults with chronic low back pain [7, 83-85].

Other studies have investigated the relationship between fear-avoidance beliefs and functional measures [84, 86, 87]. A study assessed how fear-avoidance beliefs affected functional parameters as well as pain in elderly individuals with low back pain participating in a physiotherapeutic programme. The patients were classified into three groups with strong, intermediate or weak fear-avoidance beliefs. Analyses revealed a decline over time of both subjective and objective measures of functional capacity in the group with high fear avoiders [88]. Some studies also indicate that there might be cultural differences. Among institutionalized older adults in Spanish and Brazilian samples, pain characteristics such as duration and intensity were show to explain significantly more of the change in functional measures than fear-avoidance beliefs [7, 89].

Besides the mechanisms outlined in the fear-avoidance model by Vlaeyen et al. (Figure 2) increasing attention has been paid to other psychosocial factors as contributors to the perpetuation of chronic pain in younger populations [50, 90, 91]. One example is self-efficacy, which relates to the belief in one's own capacities [92]. Individuals with high self-efficacy have higher ability to manage challenging situations and setbacks than individuals with low self-efficacy, and it has been postulated that self-efficacy may be a mediator between pain-related fear/kinesiophobia and avoidance behaviour [93]. Self-perception of health is also found to be associated with the occurrence and poor recovery from chronic pain among older adults [50, 91]. However, neither self-neither efficacy nor health perceptions have been investigated in relation to kinesiophobia in older adults.

In summary, based on previous research, there is some evidence supporting the validity of the fear-avoidance model among older adults. However, the way in which different factors in the model interrelate has not been fully established. It can also be assumed that the efficacy of treatment could be improved if the patients' fear-avoidance beliefs is taken into consideration when planning a treatment regimen. Besides, far from all individuals with chronic pain develop fear-avoidance beliefs. To investigate which patients may benefit from physiotherapeutic approach considering fear-avoidance beliefs, there is also a need to identify subgroups in the population with high levels of fear of movement.

Impact of chronic pain and kinesiophobia on physical activity

The importance of physical activity-reducing age-related physical and psychological deprivations is repeatedly proven and can hence be considered established knowledge. For example, physical activity decreases the risk of cardiovascular diseases as well as some types of cancer. The benefits of staying active in high age not only affect the individual capacity on a body functional level but also influence activity and participation, e.g. affecting the number of years without disability and dependence, an important factor for both the individual and society [94]. In order to achieve such health effects, recommendations from international health guidelines state that older adults should be *"moderately physically active (i.e. a moderate amount of effort that noticeably accelerates the heart rate) at least five days a week for a minimum of 30 minutes a day"* [95]. The importance of physical activity has also been underscored in international guidelines concerning chronic pain in older adults [96, 97]. An important reason for promoting physical activity in this group is to avoid problems with multiple medications and at the same time to enhance functional capacity and well-being. Nevertheless, low activity levels are commonly reported among older adults [98-100].

For healthy older adults the aetiology of physical activity is well known and includes determinates such as younger age, being male, being married, having better health scores, previous activity levels, high self-efficacy, impaired mobility status and non-smoking [98, 101]. Yet there are reasons to believe that the aetiology of physical activity may differ in older adults who have chronic pain. For example, pain characteristics, such as long pain duration and high pain intensity have been identified as important predictors of both self-reported and performance-reported disability among older adults [99, 102] and may thus be assumed to interact with physical activity levels in older people. Whether older adults with chronic pain are less active than older adults without pain has not been established but was the objective of a systematic review [103]. Seven studies were identified as eligible for pooling 1381 older adults with musculoskeletal chronic pain with 663 asymptomatic older adults. However, due to heterogeneity between the studies, significant results could only be concluded for a subgroup of 612 older adults with chronic low back pain and 302 controls, who demonstrated a small but significant actual difference in physical activity, as those with chronic pain were less physically active.

Kinesiophobia could thus be one reason why older adults with chronic pain restrict their level of physical activity. As previously discussed, a consequence of chronic pain according to the fear-avoidance model can be limited physical activity that may lead to a cycle of more pain restriction, decreased participation, and disability [104]. For the general population the existing literature is inconsistent regarding the relationship between fear-avoidance beliefs and physical activity levels. Some results suggest that fear-avoidance beliefs may not be directly associated with reduced physical activity [99, 105, 106], but there are also several studies that conclude that the presence of fear-avoidance beliefs is significantly associated with increases in pain and reduced levels of physical activity [106, 107]. In summary, the relationships between chronic pain, pain-related factors such as fear-avoidance beliefs, and reduced physical activity are inconclusive and have not been fully investigated among older adults.

Assessment of chronic pain among older adults

Measurement of pain is central for understanding and treating pain sufficiently [108], and the bio-psychosocial model of pain addresses the need for psychosocial measures [109]. When using health measurement scales it is important that the assessment is carried out with instruments that are psychometrically sound for the specific group of patients (e.g. in terms of language and age). However, there is limited information regarding the validity and reliability of most scales measuring psychological and cognitive dimensions of pain among older populations. This is despite the fact that age-related differences in pain perception indicate that several concerns associated with the normal ageing process must be considered. For example, a valid measure must be able to discriminate between natural ageing and disease where the older person's own beliefs about pain must be considered. Moreover, age-related changes such as visual and hearing impairments as well as normal age changes in cognitive processing may hinder the older person's understanding of questions and instructions [34]. An example of this can be that older person may have difficulties comprehending long assessments. Thus, modifications of assessment protocols may be necessary to enhance compliance among older people [34]. Furthermore the heterogeneity of the group of "older people" is an important factor to reflect on because it makes chronological age a poor predictor of functional level. A consequence of the heterogeneity of older people as a group is, for example, that cut-offs most likely will vary across subgroups.

Assessment of kinesiophobia

An instrument commonly used for measuring kinesiophobia is the Tampa Scale of Kinesiophobia (TSK). Miller et al. developed the original 17-item scale in American English in 1991 for patients with musculoskeletal pain [110]. TSK has been translated into a number of languages including Swedish [111] and is widely used among several different groups of patients: e.g. low back pain [90, 112], whiplash-associated disorders [113], cancer [114] musculoskeletal pain [114, 115], shoulder disorders [116, 117] and work-related upper extremity disorder [118]. TSK was initially developed as one-dimensional measure, but during psychometrical testing some of the items have repeatedly been reported to be weak [90, 119]. As a result, several abridged versions, with different factor loadings have been published. However, there is no consensus as to which items and what factor loadings would be the preferable option. Furthermore, previous studies of the psychometrical properties of TSK have exclusively been performed among middle-aged people. This means that the psychometric properties of the TSK in relation to older adults with chronic pain have previously not been established. This is despite the fact that the high prevalence of chronic pain among older adult indicates the need to also take psychosocial factors, such as kinesiophobia, into account when assessing the pain experience among older adults.

Rationale for the thesis

Older adults should be provided with sufficient pain relief. Despite this, chronic pain is highly prevalent and management is often found to be inadequate among older adults [6]. A reason for this may be inadequate knowledge of and attitudes to pain in older populations [97]. Chronic pain, which may have severe consequences in old age [1, 7] is an important and large medical and public health issue. There is hence is a need for better understanding of the burden of chronic pain among older adults. Information about the epidemiology of chronic pain and related factors such as kinesiophobia, fear avoidance and decreased activity levels may increase the knowledge of its development among older adults and can also be important for decision and policy makers, in deciding about health budgets and prioritization. To identify which groups of patients are prone to developing pain, related factors must be explored. Previous knowledge of chronic pain among older adults has been based on cross-sectional results, in particular care settings, or in particular subgroups with certain underlying diseases, and a more generalized approach is therefore needed.

Aims

The overall aim was to explore prevalence, development and characteristics of chronic pain and kinesiophobia in older adults (with a focus on psychosocial factors and pain-related factors) and their impact on physical activity among older adults.

Specific aims

The aims of the individual papers were to study a population based cohort of older adults (65+) for the following purposes:

I. To examine prevalence, incidences and risk factors of chronic pain in different age strata of older people, and to identify risk factors for two years' persistence and new onset of chronic pain.

II. To test the construct validity, factor structure and reliability of the 11-item version of the Tampa Scale for Kinesiophobia (TSK-11, Swedish version)

III. To explore the prevalence and development of kinesiophobia and to examine the relationships between kinesiophobia, pain characteristics and cognitive affective variables.

IV. To explore possible differences in physical activity levels between older adults with and without chronic pain and to analyse the influence of pain characteristics and fear-avoidance beliefs as predictors of physical activity among those reporting chronic pain

Methods

Design

The study designs in this thesis consist of one methodological study *(paper II)* and three longitudinal cohort studies *(papers I, III & IV)*. An overall view of the papers and their design can be found in table 1.

Table 1
Overview of the papers included in the thesis

	Paper I	Paper II	Paper III	Paper IV
Design	Prospective cohort	Methodological	Cross-sectional	Prospective cohort
Sample	Total sample N=1141	Participants with chronic pain n=433 Test-retest sample n=264	Participants with chronic pain n=433	Participants with chronic pain n=433 and participants without pain n=692
Data collection	Questionnaire	Questionnaire	Questionnaire	Questionnaire
Analysis	Chi-squared test Mann-Whitney U-test Student's t-test Logistic regression analysis	Spearman's rank order correlation, Confirmatory factor analysis, Cronbach's alpha, ICC, Weighted k coefficient analysis	Paired t-test Simple and multiple Linear regression analysis	Chi-squared test Mann-Whitney U-test Student's t-test McNemar's test Wilcoxon signed rank test Paired sampled t-test Logistic regression analysis
Outcome measures	Chronic pain	Kinesiophobia	Kinesiophobia	Physical activity

Data collection

This thesis is based on data drawn from a large longitudinal population study aiming to study the health of older adults with a special focus on chronic pain. This study included older adults aged 65 years and above, selected randomly using a Swedish national register of inhabitants (SPAR), which includes all persons who are registered as residents in Sweden. A government-engaged company (Infodata) performed the randomization.

The initial sampling frame was based on an attrition of 50% and a power analysis (α=0.05, power 0.80, mean diff: 0.5, sd=1.75). The power analysis was based on previous studies comprising different instruments (e.g. MPI-S) for measuring pain. All individuals aged 65 years or older were eligible for inclusion and no other exclusion criteria were used. Data were collected from May 2011 to May 2013.

Questionnaires were sent to respondents at baseline, after 12 and 24 months. To increase the response rate at the 24-month follow-up, questionnaires were sent to all respondents who replied at baseline. The questionnaires were distributed by post together with an accompanying letter explaining the aim and procedure of the project. Questionnaires were requested back with enclosed self-addressed/prepaid envelopes. Reminder letters were sent after two weeks. The 12- and 24-month follow-up followed the same procedure as the baseline sampling procedure.

Respondents

Response rate of the total sample

At baseline a total of 1,141 questionnaires were completed and returned. Reasons for non-participation are reported in the flowchart seen in figure 3. The overall response rate at baseline was 57.8%. At the 12-month follow-up a total of 782 (88.4%) questionnaires were returned. To increase the response rate at the 24-month follow-up, questionnaires were sent to all respondents who replied at baseline, n=1,044 (no questionnaires were sent to those who were reported to be deceased, n=50, declined continued participation, n=46 or emigrated, n=1 before the last questionnaire mailing). At the 24-month follow-up 843 (81.2%) completed the follow-up questionnaires.

Chronic pain sample

Among those replying to the baseline questionnaire, 433 (37.9%) reported to be suffering from chronic pain (pain duration >3 months) (63.5% women, mean age 74.8, 65–78 years) and this group constituted the chronic sample used in all papers.

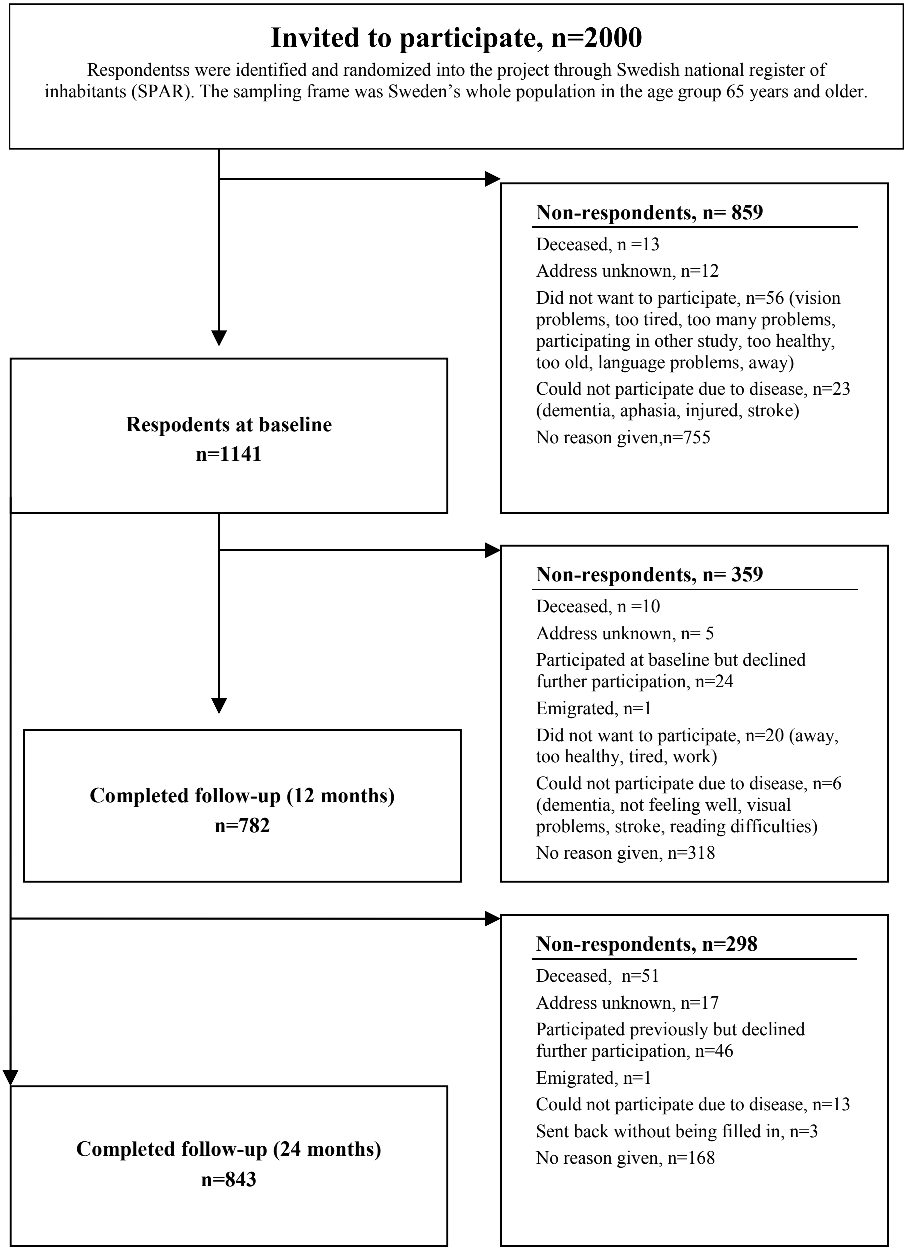


Figure 3.
Flowchart of respondents in the study. The respondents were followed up at 12 and 24 months after baseline.

Table 2.
Description of the sample at baseline and population, divided by age groups

Variable	Total sample	65–74 years	75–84 years	85+ years
Total population				
N, (%)	1 784 713	979 895(54.9)	551 446(30.9)	253372(14.2)
Men/woman, (%)	45.2/54.8	49.1/50.9	43.5/56.5	33.5/66.5
Age, mean	74.9	68.9	79.1	88.8
Target population				
n, (%)	2000	1033(51.7)	664(33.2)	303(15.1)
Men/woman, %	45.9/54.1	50.0/50.0	45.9/54.1	32.3/67.7
Final sample				
n, (%)	1141	637(56.1)	367(32.2)	133(11.7)
Response rate, (%)	57.0	61.7	54.4	43.9
Men/woman, (%)	46.5/53.5	47.6/52.4	47.4/52.6	38.2/61.7
Reporting chronic pain, (%) [a]	38.5	38.6	34.5	47.7
Age, mean	74.7	69.5	79.0	88.8
P-values for comparison of gender between the final sample and total population [b]	0.388	0.452	0.140	0.233
P-values for comparison of gender between the final sample and target population [b]	0.365	0.365	0.649	0.230

[a] Pain of duration ≥ 3 months
[b] Chi –square test

Drop-out and attrition over time

Drop-out at baseline

The only variable available for drop-out analysis of those not participating at baseline was gender, for which no significant difference (p=0.322) was found between respondents (53.2% women) and non-respondents (55.8% women). In a subsequent analysis, the study sample was compared to the target sample and the total Swedish population in three age strata. Nor did these analyses show any differences regarding gender distribution (Table 1).

Attrition over time for the total sample

When analysing the attrition over time, those lost to follow-up differed regarding age, living arrangements and material status at both 12- and 24-month follow-up (Table 4).

Attrition over time for the chronic pain sample

An analysis of the attrition of those who reported chronic pain (n=433) at baseline and also replied at the 12-month follow-up (n=284), indicated that those who were lost at follow-up were slightly older (mean age 78.4 vs. 74.4 years) ($p > 0.000$) but only revealed minor differences for sex, pain intensity and pain duration (table 3).

The same pattern was found when analysing the attrition for the chronic pain sample between baseline and the 24-month follow-up (n=310). The mean age of the respondents at the 24-month follow-up was lower (mean age 73.9 years) compared to the non-respondents (mean age 77.5 years) ($p > 0.000$), whereas no significant differences were found for gender, baseline measures of pain intensity and duration (table 3).

Table 3.

Attrition analyses for the total sample baseline to 12- and 24-month follow-up

	12-MONTH FOLLOW-UP			**24-MONTH FOLLOW-UP**		
	Respondents	**Non-respondents**	**P-value**	**Respondents**	**Non-respondents**	**P-value**
Mean age, (SD)[a]	**74.2 (7.0)**	**76.0 (7.7)**	**0.000**	**73.8 (6.8)**	**77.4 (7.9)**	**0.000**
Male/female [b]	**46.3/53.7**	**46.8/53.2**	0.898	45.3/54.7	46.9/53.1	0.685
Living arrangements [b]						
Own accommodation	98.7	94.3	**0.000**	**99.0**	**92.4**	**0.000**
Special housing	1.3	5.7		**1.0**	**7.6**	
Marital status[c], n (%)			**0.014**			**0.000**
Married	472(60.5)	185(52.1)		516(61.4)	141(48.0)	
Single	64(8.2)	32(9.0)		78(9.3)	18(6.1)	
Widow/widowed	147(18.8)	91(25.6)		145(17.2)	93(31.6)	
Divorced	97(12.4)	47(13.2)		102(12.1)	42(14.3)	

[a] Student´s t-test
[b]Chi squared test
[C]Mann-Whiteny U-test

Measurements

The questionnaires contained questions about: sex, age, weight (kg), height (m), smoking habits (“No, I have never smoked”, “Yes, but I have quit”, “Yes, occasionally”, and “Yes, daily”), housing (own home or special housing) and living arrangements (alone or with someone) and marital status.

Acute and chronic pain

Chronic pain, defined as pain that had lasted longer than three months [20], was noted by responding yes or no to the question "Have you been troubled by pain for the last three months or more?" "Acute pain" was identified by the respondents' answer to the question "Have you been bothered by pain in the last week" (yes/no).

Age-related symptoms

Sleeping problems, depressed mood, fatigue and mobility problems were measured using a battery of questions about health symptoms previously used among older adults (*papers I & III*) [5, 120]. It was measured as follows: "During the past three months have you been troubled by e.g. sleeping problems?" and the equivalent question for depressed mood, fatigue and mobility problems. Each question had four response alternatives: "no, not at all", "yes, little", "yes, rather much" and "yes, very much". The responses were dichotomized into Yes ("yes, little", "yes, rather much" and "yes, very much") and No ("No, not at all").

Self-rated health

Self-rated health (*papers III, IV*) was measured using an item extracted from the 12-item Short-Form Health Survey (SF-12) [121]. The SF-12 measures health-related quality of life. The item used was: "How would you generally like to say that your health is?" The item had five alternative responses: ("Excellent health", "Very good health", "Good health", "Fair health" and "Poor health"). A high score indicates better health. SF-12 has been found to be valid and reliable in Swedish older adults [122].

Instruments

Multidimensional Pain Inventory – Brief Screening version

Pain characteristics (intensity, duration, location) and impact of pain on psychosocial factors (*paper I*) was measured using the Brief Screening version of the Multidimensional Pain Inventory (Swedish version) [123]. The scale consists of four subscales (pain severity, interference, life control, affective distress) including a total of eight items, all having seven response alternatives (0=No, not at all, 6=Yes, very much). High scores in the subscales are interpreted as high levels of pain severity, pain interference, life-control and affective distress. The psychometric properties of the Brief Swedish Screening Version of MPI have shown acceptable validity and reliability among older adults, aged 60–89 years [124].

Pain characteristics (intensity, duration, location) were also measured using single items extracted from the subscale "Pain severity". Pain intensity was measured using the item "Rate the average level of your pain during the past week" with responses on a 6-point Likert scale ranging from No pain at all (1 point) to Tremendous amount of pain (6 points). Duration of pain was measured in years. Primary pain location was also identified by an open response to the question "What is your primary pain location?" Before statistical analysis the responses were categorized into the following seven categories: upper extremities, shoulder and neck, lower extremities, thorax and abdomen, back and pelvis, head and other locations (including hand and feet). The respondents were also asked if, in addition to the primary pain location, they had pain elsewhere (yes/ no) and if they were using any pain medication (yes/no).

Tampa Scale of Kinesiophobia (TSK-11)

Kinesiophobia (excessive fear of movement/(re)injury) related to pain (*papers II, III, IV*) was measured with the Tampa Scale of Kinesiophobia) [30]. In this study, an 11-item version (TSK-11) proposed by Woby et al. [90] was used. The Tampa Scale of Kinesiophobia has previously been translated into Swedish (through back-forward translation) [111]. All items in TSK-11 are anchored with the answers "strongly disagree", which scores 1 point, and "strongly agree", which scores 4 points. The total summary score is calculated and can range between 11 and 44 points. A high score indicates strong fear of movement/ (re)injury, i.e. high kinesiophobia.

A two-factor solution was used in this study. The subscale Somatic Focus (TSK-SF; belief in underlying and serious medical problems) comprises items 3–6, 8 and has a total score that ranges from 5 to 20 points. The second subscale Activity Avoidance (TSK-AA; belief that activity may result in (re)injury or increased pain) comprises items 1, 2, 7, 9–11 and has a total score of 6–24 points [119, 125].

The TSK-11 has been found to have good construct validity (correlation (r) of the TSK-11 with disability = 0.51 and with pain intensity = 0.27) and reliability (Cronbach's alpha = 0.77–0.91) when tested across various nationalities and pain populations [90, 125]. However, all previous tests were performed among young and middle-aged subjects (age 20–65 years).

Grimby's Physical Activity Scale

Levels of physical activity (I, II, IV) were measured with Grimby's Physical Activity Scale; a scale developed to evaluate self-rated physical activity in older adults [126]. Levels of physical activity were classified by one of the following responses (figure 4) to the question: "How physically active do you think you have been during the past six months?"

Level of physical activity	
Hardly any physical activity.	Inactive
Mostly sitting, sometimes a walk, light gardening or similar tasks, sometimes light household activities such as heating up food, dusting or clearing away.	
Light physical exercise around 2–4 hours a week, such as walks, fishing, dancing, ordinary gardening etc. including walks to and from shops. Main responsibility for light domestic work such as cooking, dusting, clearing away and making beds. Performs or takes part in weekly cleaning.	
Moderate exercise 1–2 hours a week, such as jogging, swimming, gymnastics, heavy gardening, home repairs or light physical activities more than four hours a week. Responsible for all domestic activities, light as well as heavy. Weekly cleaning such as doing vacuum cleaning, washing floors and window cleaning.	Active
Moderate exercise at least three hours a week such as tennis, swimming, jogging etc.	
Hard or very hard exercise regularly and several times a week where the physical exertion is great, such as jogging or skiing.	

Figure 4
Description of levels of physical activity was classified with Grimby's Physical Activity Scale; a scale developed to evaluate self-rated physical activity in older adults [126].

Response options 4–6 have previously been used to correspond to WHO's recommended levels of physical activity [107]. In studies II and IV, physical activity was thus dichotomized into inactive (including response options 1–3) and active (including response option 4–6).

Grimby's Physical Activity Scale has been psychometrically evaluated in older adults and has demonstrated acceptable construct validity when validated against measures of physical performance [127, 128]. It also demonstrated acceptable construct validity when validated against various physical measures and has been found to be able to discriminate between groups who were more active and less active, as assessed by measuring maximal oxygen uptake [127].

ADL Staircase

Activity dependence/disability (*papers I, II*) was assessed by the ADL Staircase. The ADL Staircase is a Swedish instrument development from Katz's Index of Independence in Activities of Daily Living [129, 130] and measures dependence in 10 everyday activities, divided into the dimensions of Personal ADL (bathing, dressing, toileting, transferring, continence, and feeding) and Instrumental ADL (cooking, transportation, grocery shopping and cleaning). After the first grading (dependent or independent) the results are graded a second time using an 11-graded scale, where 10 represents total dependence and 0 represents independence in all activities. When psychometrically tested among older people, the scale demonstrated acceptable construct validity and high values for reliability regarding internal consistency (Cronbach's α for internal consistency: 0.80–0.90) [131].

General Self-efficacy Scale

Self-efficacy was measured (*papers III, IV*) using the General Self-Efficacy Scale (GSE), a generic instrument that aims to measure “optimistic self-beliefs to cope with a variety of difficult demands in life”, recommended for use among adults with chronic pain [132]. The scale consists of 10 items with alternative responses: 1 = “not at all true”, 2 = “hardly true”, 3 = “moderately true” and 4 = “exactly true”. A sum score, ranging from 10 to 40, is calculated. A high score indicates high self-efficacy. The scale has commonly been used in older adults as well as in pain patients [133] and has been translated into Swedish [134]. The GSE has been tested for its psychometric properties and has demonstrated good validity and reliability (Cronbach’s alpha for internal consistency = 0.75–0.91) and good test-retest reliability (r=0.55–0.67) [135].

Analysis

Psychometric testing

The psychometric properties of the Tampa Scale of Kinesiophobia (TSK-11) were analysed with regard to: floor/ceiling effects, response frequency (item response rate and overall response rate), factor structure (confirming factor analysis), construct validity (convergent validity, corrected item-total correlations) and reliability (internal consistency and test-retest reliability) as follows. Floor and ceiling effect was considered to be present if more than 15% of the sample chose the highest or lowest option.

The factor structure of the instrument was examined by confirmatory factor analysis using LISREL statistical software version 8.80. Based on previous research on factor structures of the TSK-11, a two-factor solution (TSK-AA, TSK-SF) and a one-factor solution (TSK-11) were tested [119, 125]. Confirmatory factor analysis was used to statistically determine whether previously established models fitted the shared variance of the measured variables using Spearman’s rank order correlation matrix. To measure the model’s fit, the following goodness-of-fit tests were performed; the goodness of fit index (GFI), adjusted goodness of fit index (AGFI), normed fit index (NFI), and comparative fit index (CFI), all of which can range between 0 (no fit at all) and 1 (perfect fit). They have no absolute threshold levels for acceptability, but values of 0.85–0.95 are generally considered to indicate acceptable fit to the model and values of 0.90–0.97 good fit. The root mean square error of approximation (RMSEA) was also calculated; it is considered acceptable when its value is 0.08, but a value of 0.05 is desirable [136].

Construct validity

Construct validity (how closely the scale is related to other variables/measures of the same construct) [137] was analysed using Spearman's rank order correlation. Based on the theoretical framework presented in the cognitive behavioural fear-avoidance model by Vlaeyen and Linton (2000), a positive correlation between kinesiophobia (TSK) activity/ADL dependence (ADL Staircase), and pain intensity (numerical rating scale) were hypothesized. In addition a negative correlation was hypothesized between kinesiophobia (TSK) and physical activity (Grimby's Physical Activity Scale) [8, 90, 107, 119, 138-140].

Corrected item-total correlations reflect the construct validity and homogeneity of an instrument and were used to measure how well one individual item correlated with the total score for the remaining items when it is omitted.

Item-total correlation analysis was performed to check whether any item in the set of tests was inconsistent with the averaged behaviour of the others. It is recommended that a value of < 0.2 be interpreted as an indication that the individual item does not correlate well with the other items and should therefore be discarded from the instrument [137]. A value >0.2 is desirable and values >0.3 can be considered more suitable.

Reliability

Internal consistency was evaluated by Cronbach's α (Cronbach, 1951). Generally, values of 0.7–0.9 are considered to indicate good reliability. Values <0.7 could indicate that some of the items are too heterogeneous. On the other hand, a value >0.9 may indicate a high level of item redundancy [136].

Test–retest reliability (i.e. correlation agreement between two assessment time points – baseline (t) and follow-up at 2 weeks (t1) – was analysed for the total TSK score and for individual items.

Test-retest reliability for the total score was analysed by determining the intra-class correlation coefficient (ICC) and confidence intervals. ICC values of 0–0.2 indicate poor agreement; values of 0.3–0.4 indicate fair agreement; values of 0.5–0.6 indicate moderate agreement; values of 0.7–0.8 indicate strong agreement; and values > 0.8 indicate almost perfect agreement [137].

Agreement for the individual items in the test–retest analysis was assessed by weighted k analysis [137]. k-values of < 0.20 represent poor reliability; values of 0.21–0.40 indicate fair reliability; values of 0.41–0.60 indicate moderate reliability; values of 0.61–0.80 represent good reliability; and values >0.80 are considered to represent very good reliability [141].

Data were analysed using PASW 20.0, VassarStats (http://www.vassarstats.net) and LISREL statistical software version 8.80.

Statistical analysis

In all papers (I–IV) statistical significance was set at $p < 0.05$ and analyses were done using SPSS Statistics, (version 18.0 in paper II and version 21 in papers I, III, IV) (SPSS Inc., Chicago, IL).

For descriptive data (*papers I–IV*) mean, standard deviations were calculated for continuous variables and range and percentiles were used as descriptive measures for categorical data. The chi-squared test was used to compare categorical data (*papers I, IV*); the Mann–Whitney U-test was used for ordinal data (*papers I, IV*) and the Student's t-test for interval/ratio data (*papers I, IV*). McNemar's test (*paper IV*), the Wilcoxon signed rank test (*paper IV*) were used between groups, and the paired sample t-test (*papers III, IV*) were used for paired group comparisons.

Cumulative incidence (*paper I*) was calculated by the number of individuals who developed chronic pain during follow-up (two years) divided by the number of older adults without pain at baseline.

BMI was calculated (weight in kg/ height in m^2).

Associations for baseline demographic, cognitive-affective and pain-related variables were estimated as a function of kinesiophobia (TSK-11) in paper III. TSK-11 was regarded as data on the interval scale and thus simple and multiple linear regressions were used. Variables with p-value <0.05 in the univariate analysis were retained and included in the multiple linear regression analysis. Both B coefficients and the standardized coefficients beta (β) were reported [142]. An adjusted goodness of fit, $R2^{adj}$, was calculated to estimate the total variance explained by the model. Multi-collinearity was tested by examining tolerance (≥ 0.10) and the Variance Inflation Factor (≤10) [142].

In papers I and IV binary variables (physical activity and chronic pain) were evaluated. Logistic regression analyses were thus the option to use. Two binary logistic regression analyses (backward stepwise likelihood ratio method) were used to identify baseline characteristics and predictors of physical activity (*paper IV*). As the dependent variable, physical activity was dichotomized into inactive (1–3) and active (4–6) [107]. Demographic variables (housing and living arrangements), pain-related variables (intensity, duration), psychological variables (kinesiophobia and self-efficacy), and health-related variables (BMI, self-rated health) were entered as independent variables (*paper IV*).

In paper I several binary logistic regression analyses were used to identify baseline predictors of onset and persistence of chronic pain. This was made in an explorative approach for the total sample at 12- and 24-month follow-ups. The dependent variables were "Chronic pain persistence" (pain of duration > 3 months at both baseline and follow-up) and “Chronic pain onset” (no pain at baseline but pain of duration > 3 months at follow-up). Demographic variables (age, gender, living arrangements and BMI), pain characteristics (intensity, duration, more than one pain location, pain medication and acute pain at baseline, age-related symptoms (fatigue, sleep problems, mobility problems, depressed mood), physical activity and ADL dependence was entered as independent variables. In a second step, multiple logistic regressions analysis was used to identify risk factors for chronic pain persistence at the 12- and 24-month follow-up. This analysis was performed separately for men and women. Based on variables, significant levels ($p < 0.05$) in the bivariate analysis were BMI, pain intensity, pain duration, pain in more than one location and MPI severity, entered as independent variables. Results of all logistic regression analyses were presented as Odds Ratios (OR) with 95% confidence intervals (*paper I, IV*).

The quality of the logistic models was tested by the Hosmer-Lemeshow goodness-of-fit test and Nagelkerke’s R-squared test. A non-significant value ($p > 0.05$) indicates a good model fit in the Hosmer-Lemeshow goodness-of-fit test [143].

Ethical considerations

In research involving the participation of humans, it is important to consider the ethical guidelines for human research. This study was approved by the regional Ethical Review Board in Lund (registration no. 2010/683), and in accordance with the basic ethical principles of medical research [144, 145]. The principle of respect for autonomy, the principle of beneficence and non-maleficence and the principle of justice have been affirmed [146].

Principle of respect for autonomy

This principle refers to a person’s rights to hold views, to make choices and to take actions based on personal values and beliefs [146]. This means that understanding and voluntariness must be ensured and that the respondents have the information they need to independently make an informed decision whether to participate or not. All participation in the study has been on a voluntary basis. Written information about the study purpose and procedures has been provided all through the process. Informed written consent to participate was collected both in the mailing of the initial questionnaire and at each of the follow-up mailings (12 and 24 months). Respondents were also informed that they could withdraw their participation at any time without explanation, and a phone number was attached to every mailing, encouraging the respondents to contact the project administration if any questions should arise.

Principle of beneficence and non-maleficence

Beneficence refers to the well-being of the respondents while non-maleficence means that no harm should be knowingly caused [146]. Risk versus benefits should hence be carefully weighted under this principle. Data from respondents have been treated with confidentiality all through the processes of research, and all people involved have been kept anonymous for publication. Each respondent was awarded a code number which was used for identification of the questionnaires and in the database. A list of code numbers of each respondent has been kept in locked cabinets and separated from the database.

The possible risk of feeling uncomfortable or of privacy intrusion was deemed to be relatively small compared with the direct and indirect benefits. The study aimed to improve the care of older people with chronic pain. Hence the study provided an indirect rather than direct benefit for the respondents. A direct benefit could be that this patient situation is observed and dealt with; this may be perceived positively by the respondents. The risk of harm either physically or mentally from participating in the study was hence considered to be small.

Principle of justice

The last principle refers to the ethics of fairness and that all people should be treated equally [146]. No one person should thus bear more of burden than other people and all should have an equal share in any benefits. If the benefits do not directly affect the respondents, they should benefit a similar population in the future [146]. The whole of Sweden was used as sampling frame and no exclusion criteria were used except for age (under 65 years). By selection of respondents through randomization, all have been given the same opportunity to participate. The study aimed to increase the knowledge about chronic pain among older people and will thus affect the care and treatment of chronic pain in future populations of older adults.

Results

Chronic pain among older adults

At baseline 433 (38.5%) of the respondents reported having had pain for more than three months. Respondents who reported chronic pain were to a greater extent women, lived alone, or were divorced and unmarried compared to those without chronic pain ($p<0.05$).

Table 4.
Characteristics of the participants at baseline, divided by participants reporting no pain versus chronic pain[a] (N=1141)

	No Pain (n=708)	**Chronic pain (n=433)**	**P-value**
Male/ female (%)	53.2/46.8	36.5/63.5	0.016 [b]
Age, mean (SD) range	74.8(7.5)65-98	74.6(7.0)65-103	0.665 [c]
Living conditions, n (%)			0.901 b
Own accommodation	670 (97.5)	413 (97.4)	
Special housing	17 (2.5)	11 (2.6)	
Living arrangements, n (%)			0.037 [b]
Alone	217 (32.1)	163 (37.6)	
With others	460 (66.5)	263 (61.7)	
Marital status, n(%)			0.038 [d]
Married	414 (60.2)	235 (54.4)	
Single	58 (8.4)	38 (8.8)	
Widow/widowed	137 (19.9)	95 (22.0)	
Divorced	79 (11.5)	64 (14.8)	

[a]Pain of duration ≥ 3 months
[b]Chi-square test
[c]Student´s t-test
[d]Mann-Whitney U-test

Chronic pain characteristics at baseline

The sample with chronic pain was divided by age-strata to study differences over age (table 5). The mean duration of chronic pain at baseline was 10.2 years (SD 12.2). The median pain duration was five years in each age stratum except for those 85+, who had lower median duration of pain. The mean pain intensity for the total sample was 3.22 on a 6-graded scale and varied only slightly over the different age strata. The most common locations of pain were the back/pelvis and lower extremities, followed by the upper extremities, shoulder/neck, thorax/abdomen, "other" and head. When comparing pain locations over the different age strata no clear patterns or age-related differences could be identified, except for the location "lower extremities" that doubled with age. One third of the respondents with chronic pain had not received any pain diagnosis. A majority of the respondents made use of pain medication, with the youngest age group being those that used the least and the oldest aged group using the most.

Table 5.
Pain characteristics at baseline in respondents reporting chronic pain[a], divided by three age strata

	Total chronic pain sample (n=433)	**65–74 years (n=247)**	**75–84 years (n=122)**	**85+ years (n= 59)**
Pain duration in years, median (q3–q1)	5.0 (14.00–2.00)	5.0 (14.00–2.00)	5.00 (15.00–2.00)	3.5 (10.00–2.00)
Pain intensity [b], mean (SD), range	3.2 (1.1) 1–6	3.16 (1.06) 1–6	3.30 (1.04) 1–5	3.34 (1.38) 2–6
Received pain diagnosis, %	66.5	69.1	58.6	73.7
Primary pain location, %				
Lower extremities	30.7	26.2	34.2	40.4
Back / pelvis	34.1	35.0	36.0	28.1
Upper extremities	13.4	15.6	9.9	12.3
Shoulder /neck	10.2	12.2	5.4	10.5
Thorax / abdomen	4.6	3.8	7.2	3.5
Head	3.9	4.2	3.6	3.5
Other	2.9	3.0	3.6	1.8
> One pain location, %	43.5	43.9	38.5	51.7
Using pain medications, %	58.2	46.3	68.8	69.5
MPI scores[c], mean (SD)				
Pain severity	3.0 (1.06)	3.03 (1.04)	3.17 (1.05)	3.28 (1.17)
Interference	3.14 (1.67)	2.89 (1.57)	3.29 (1.78)	3.88 (1.62)
Life Control	4.52 (1.30)	4.70 (1.27)	4.39 (1.34)	4.00 (1.49)
Affective Distress	2.36 (1.33)	2.28 (1.30)	2.54 (1.39	2.40 (1.14)

[a]Pain of duration ≥3 months
[b]Pain intensity = "average level of pain in the last week", measured using a 5-point Likert scale with answers ranging from "No pain at all" to "Tremendous amount of pain"
[c]MPI score ranging from 0–6 (high score indicate high pain severity, interference, life control, affective distress).

Prevalence, changes over time, and cumulative incidence

The estimates of pain prevalence at 12- and 24-month follow-up were 35.4% and 33.5% respectively. Of those who had pain at baseline, and responded at follow-up, 93.5% were still in pain after 12 months and 87.9% were still in pain after 24 months.

Of those not reporting chronic pain at baseline, and who replied at the follow-up times, 74 reported chronic pains at the 12-month follow-up, 75 at the 24-month follow-up. The cumulative incidence was estimated to be 5.4% annually. Being female, having lower BMI, reporting more than one pain location, higher severity, and longer duration were associated with persistence of chronic pain, but not for men when divided by gender. Younger age was associated with new onset of chronic pain.

Factors related to chronic pain

Responders with chronic pain reported significantly higher levels of mobility problems (61.8% vs. 38.2%), depressed mood (38.8% vs. 22.4%), compared with those not reporting chronic pain (*papers I & IV*). Also sleep problems were more common among respondents without chronic pain (47.8% vs. 52.1%) (*paper I*).

Respondents with chronic pain were also more often found to report fair and poor health and reported to a lesser extent very good or excellent health when compared to respondents without chronic pain *(paper IV).* The response option "Poor health" showed the largest decrease over time from 5.3% at baseline down to 3.5% at follow-up (*paper IV*). Among the respondents with chronic pain who reported poor health, the mean age was 80.1 years, 43.8% were living alone and 68.8% were living in their own accommodation, and a majority (81.1%) was women *(paper III).*

When the impact of pain on psychosocial factors was measured by the brief screening version of the Multidimensional Pain Inventory*, (paper I)* higher scores were found in the older age strata for the subscales "Pain severity" and "Interference" and "Affective distress". At the same time, the subscale "Life control" decreased with age (table 5).

Predictors of persistence of chronic pain (papers I & IV)

In paper I, the 12- and 24-month follow-up was used to identify predictors of persistence of chronic pain. The unadjusted regression model showed that more than one pain location predicted persistence of chronic pain at both time points. Female gender and lower BMI were also associated with still having chronic pain

12 months later, whereas high pain intensity (OR=1.65, 95% CI=1.06–2.56), long pain duration (OR=1.08, 95% CI=1.01–1.15) and higher score on the MPI (OR=1.79, 95% CI=1.13–2.83) subscale pain severity were associated with chronic pain 24 months later. A similar pattern was observed for these variables at the 12-month follow-up; however these numbers were not considered significant. When the sample was divided by gender no variables remained significant for men at either of the two time points. Multiple regression models for the 12- and 24-month follow-up were also performed, but no stable models could be identified.

Predictors of new onset of chronic pain (paper I& IV)

The 12- and 24-month follow-up was also used to identify possible predictors of chronic pain onset (*paper I*). In the unadjusted logistic regression analysis mobility problems (OR= 2.77, 95% CI=1.08–7.08) were identified as predictors of new onset of chronic pain 12-months later. Increased age (OR=0.94, 95% CI=0.89–0.99) gave a decreased risk of new onset of chronic pain. Multiple regression models for the 12- and 24-month follow-up was also tested for the pain onset, but again could no stable model be identified.

Kinesiophobia among older adults

Psychometric properties of TSK-11

When evaluating the psychometric properties of TSK-11 in paper II, item response rates ranged between 82.9 and 87.1% and a total score for the instrument could be calculated for 75.8% of the respondents. The highest score of 44 points was obtained by 5.3% of the respondents and 0.7% obtained the lowest score of 11 points. Thus no floor or ceiling effects were found for the total score.

Factor structure

Confirmatory factor analysis showed that both one- and two factor-solutions were possible. The factor loadings ranged between 0.57 and 0.83 for the two-factor solution and between 0.49 and 0.82 for the one-factor solution. However, the factor loadings were slightly higher for the two factor-solution (chi-square = 255.8; df, 43) compared to the one-factor solution (chi-square=339.9; df, 44). The two-factor model also provided a better fit to the data than a one-factor model, as the difference in chi-square values between the one-factor and two-factor models (about 84) is itself chi-square distributed, with the number of degrees of freedom being the difference between the df values for the two models (i.e. 1).

Furthermore, the goodness of fit analysis also showed a slightly better fit for the two-factor solution (table 6).

Table 6.
Fit of the data according to confirmatory factor analyses

Item	One-factor model	Two-factor model	Criterion[a]	
	Total TSK-11	Somatic Focus (SF) + Activity Avoidance (AA)	Good fit	Acceptable fit
Goodness of fit index (GFI)	0.877	0.909	≥0.95	≥0.90
Adjusted goodness of fit index (AGFI)	0.816	0.859	≥0.90	≥0.85
Normed fit index (NFI)	0.913	0.934	≥0.95	≥0.90
Comparative fit index (CFI)	0.923	0.945	≥0.97	≥0.95
Root mean square error of approximation (RMSEA)	0.124	0.103	≤0.05	≤0.08

[a]Schermelleh_Egel, Moosbrugger, and Müller (2003)

Validity

Corrected item total correlations were 0.34–0.74 for the TSK-11 and 0.36–0.55 and 0.57–0.72 for the TSK-SF and TSK-AA subscales, respectively. Evidence of convergent validity was shown by significant positive correlations with activity/ADL dependence (r=0.2) and pain intensity (r=0.3), and a significant negative correlation with physical activity (r=–0.3). The TSK-SF and TSK-AA subscales showed similar but slightly weaker correlations with the ADL Staircase and Grimby's Physical Activity Scale. Grimby's scale was significantly correlated with both TSK-11 and TSK-AA. Pain intensity showed the strongest correlation with TSK-SF.

Reliability

The internal consistency of the TSK-11 was found to be acceptable for all factors and Cronbach's alpha coefficients ranged between 0.74 and 0.87. Cronbach's alpha coefficients if an item was deleted ranged between 0.67 and 0.70 for TSK-SF and between 0.81 and 0.84 for TSK-AA. Test-retest analysis of total TSK score showed strong agreement regarding the ICC (r=0.747, 95% CI 0.64–0.82). The weighted kappa coefficients for the individual items showed moderate reliability (range 0.41–0.58), with the exception of items 1 and 6, which showed fair reliability.

Prevalence, changes over time, and related factors

The mean level of kinesiophobia at baseline was 22.8 (SD 8.3) *(papers II, III, IV).* High levels of kinesiophobia (TSK-11 >35) were seen in 10% of the subjects among frailer and older adults predominantly living in special housing, but independently of sex. The mean level of kinesiophobia remained unchanged over time ($p=0.97$). However, individual changes over time in TSK-11 scores were seen among 89.8% of the subjects and ranged between –26 and 24 points *(paper III).*

The univariate analysis yielded no significant associations between kinesiophobia and the variables gender and pain location. Age, pain intensity and living conditions, self-efficacy and “General health-perceived as fair and poor” were all statistically significant associated ($p<0.05$) with baseline kinesiophobia. When these variables were entered into the multiple linear regression analysis in a second step, significant associations with higher levels of kinesiophobia ($p<0.05$) were found for “pain intensity” ($\beta=1.22$) and “general health” perceived as poor ($\beta=8.71$). However, when comparing the beta values, the strongest association was found for pain intensity ($\beta=0.44$) compared to $\beta=0.26$ for poor health. The adjusted R squared value was 0.175. No multi-collinearity problem was detected for any of the models (*paper III*).

Impact on physical activity

In *paper IV*, respondents with chronic pain were found to be significantly less active (31.1%) than those without chronic pain (56.9%) ($p<0.001$). In the total sample, men reported significantly higher levels of physical activity than women ($p<0.001$), whereas in the chronic pain sample there was no difference regarding sex. For the subsample with chronic pain, logistic regression analyses were performed to assess associations between baseline physical activity and variables previously shown to be related to physical activity levels. At baseline, low age (OR=0.89, 95% CI=0.84–0.94), low BMI (OR=0.92, 95% CI=0.85–0.96), high self-efficacy (OR=1.12, 95% CI=1.06–1.19) and lower levels of kinesiophobia (OR=0.93, 95% CI=0.88–0.95) showed statistically significant associations ($p<0.01$) with reaching sufficient levels of physical activity (scoring > 4 points on Grimby’s Physical Activity Scale).

Predictors of physical activity in older adults with chronic pain

The 12-month follow-up was also used to identify potential predictors of physical activity levels *(paper IV)* among the subsample with chronic pain. The results of the logistic regression analysis showed that lower age (OR=0.93, 95% CI=0.88–0.99), low kinesiophobia OR=0.95, 95% CI=0.91–0.99), and higher activity level at baseline (OR=10.0, 95% CI=4.98–20.67) significantly predicted higher levels of physical activity in individuals with chronic pain.

Discussion

Methodological considerations

The sampling method provided a large randomized national sample of older adults, and together with the use of standardized definitions and validated measures the potential for selection bias was reduced. However, some methodological issues must be considered when interpreting these findings. Aspects of the internal, external and statistical validity of this thesis are therefore discussed below.

Internal validity

Internal validity refers to the extent to which the result of the study reflect the true situation in the study sample and are not results of chance, bias or confounding [147]. Firstly, the results of the study are based solely on self-reported measurements. In all papers the subjective nature of chronic pain must be considered as the definition of chronic pain (constant or intermittent pain for at least three months) provided a relatively rough estimate of chronic pain, which did not make it possible to distinguish new pain from recurrent pain. However, the lack of precision allowed a larger data collection within a national sample. In *paper IV*, it must also be considered that Grimby's Physical Activity Scale gives a quite crude measurement of physical activity. Objective measurement, using accelerometers for example, might have identified smaller changes and decreased the risk of recall bias. There is also documented underestimation of inactivity for self-report questionnaires [148] and hence the true prevalence of inactivity may be even higher than that reported in the present study. However, a self-report questionnaire was deemed to be preferable due to the large sample size in this study. In addition, an important strength of Grimby's activity scale is that it was developed for older adults and it has been shown to distinguish between active and non-active people. It is thus a superior choice for use in older adults compared to other available instruments for measuring physical activity, e.g., IPAQ, which has been shown to have questionable psychometric properties in this group [149]. Long durations of chronic pain at baseline may also have influenced the internal validity, especially for the question pain duration, which may have been induced by recall bias, i.e. participants who have had pain for a long time may have become used to it and will no longer remember what it was like to not be in pain. In *paper II*, other confounding factors than those investigated may underlie the association between the independent variables and outcomes chronic pain and physical activity in older adults. In paper II, such determinants may include comorbidity and socioeconomic variables but also factors relating to the built environment, such as walkability, which previously have been shown to be related to physical activity in older adults [150, 151]. Unfortunately these factors were not possible to consider in this study. Also the effect of cognitive status and the role of proxy responders have not been investigated and all interpretations must be made with this in mind.

External validity

External validity refers to the generalizability of results and there are several sources of bias that can threaten the external validity of the results [147]. For example, a low response rate, if the drop-out is systematic, could be a threat to the external validity of a study. In this study the response rate was 57% at baseline; this can be considered relatively low but corresponds to response rates in similar studies of older people [152]. However, it can also be seen that the response rate differed over the ages and was lowest in the oldest age groups. This means that it is much likely that the people in our sample were slightly younger and healthier than the true population. It is possible that a stratified selection procedure could have made it easier to include more frail elderly people in the oldest age group, but then it would have become difficult to generalize on the population level. The independent randomized selection procedure used in the present study made it easier to generalize but at the price of a healthier sample and probably a slight underestimation of results. However, when comparing our sample to the target population, and the total population of Sweden, no significant differences were found regarding gender distribution or mean age in any age groups. This, together with the result from the attrition analysis comparing the respondents and non-respondents, where no significant differences ($p=0.322$) were found for gender, indicates that our sample corresponds to the national population and that the drop-out may not have been systematic.

Extensive loss to follow-up is another problem in prospective studies, especially when studying older populations. Data collected by questionnaires may result in an under-sampling of older people who are not able to comprehend the data collection, and thereby increase the risk of selection bias. Drop-out to follow-up due to death and illness was common in our sample, representing 25% of the drop-out at the 24-month follow-up. However an analysis of the attrition among those with chronic pain replying at baseline (n=433) and follow-up indicated that those lost at follow-up were slightly older (mean age 78.4 years vs. 74.39 years) but only revealed minor differences for sex, pain intensity, and pain duration.

Statistical conclusion validity

Statistical conclusion validity refers to the degree to which conclusions about the relationship among variables are correct or "reasonable". Primarily, two types of errors can occur: type I (finding differences in the sample that do not exist in the true population) and type II error (failing to detect differences in the sample though they exist in the true population) [153]. Regarding the statistical significance of our results, the p-value was set at p=0.05. However, a majority of the results were significant at a level of <0.001, that is, the risk of type 1 error was less than 1%. Since no comparison was made for more than two groups the risk of mass significance was considered to be low. Type II error answers the question whether we could have missed a true association. By conducting a power analysis prior a study, the sample size can be estimated so that the risk of Type II error can be minimized. A power analysis was also conducted before the data collection, but this was based on a wider aim of a larger population study, which aimed to study chronic pain and many other aspects of health among older adults. The power analysis was hence not based on the main outcomes of the present studies. Significant results were obtained in most analyses and when descriptively studying the results, the identified differences seemed realistic. Hence, the risk for low power was considered small in *papers I–IV*. By including a larger sample even more significant results might have been achieved, although probably not clinically relevant. The only analyses in which power probably was not achieved were the regressions regarding the onset of chronic pain (*paper I*). However, it is likely that this may be due more to the occurrence of new pain, i.e. too few developed pain during the two years. To have been able to achieve power in these analyses, a much larger sample size would most likely have been needed. However, including so much larger a sample size in this exploratory stage would have been ethically questionable. That prediction models were poor was perhaps above all because the follow-up period should have been longer, which would have been interesting to see, but it would probably to a large extent have been affected by an increased attrition.

General discussion of the result

The results of this thesis showed that chronic pain in a Swedish national representative sample of older adults was highly prevalent, stable over time and increased at the age of 85 years. Both onset and recovery from chronic pain occurred during 2 years, and pain characteristics such as intensity/severity, duration and number of locations, rather than age related symptoms and psychosocial variables, were able to predict the persistence of chronic pain. Moreover, the TSK-11 showed satisfactory psychometric properties and generally low levels of kinesiophobia were found among those with chronic pain, except among frailer and older adults living in care homes. In addition, the level of physical activity was significantly lower among those with chronic pain and significantly associated with kinesiophobia, even after controlling for age and physical activity levels at baseline.

Chronic pain

The overall prevalence of chronic pain in this study was found to be high (34.5–47.7%) and fairly consistent, until the age of 85, where an increase with age could be seen. The current literature regarding the prevalence of chronic pain in older adults is inconsistent and much of the variation in prevalence estimates has been attributed to various contexts, pain definitions and recall periods. In concurrence with the present results, increases in pain prevalence with age have previously been reported [4, 35, 154]. For example, in a large survey study (n=42,249) based on aggregated data from 17 developed and developing countries, chronic pain increased with age irrespective of country [35]. Other large surveys have reported an increase with age, although they have found that the pain intensity has been highest in the ages 45–65 years [154]. To make any direct comparisons to these studies is difficult, however, because the prevalence estimates have not been specified based on age specifically or the oldest old have been excluded (ref). However, there are also studies among community-dwelling older adults showing an increase with age. Docking et al. found that the prevalence of disabling back pain increased with age from the age of 75 years and more than doubled among those $\geq$ 90 + years (when compared to those aged 70–77 years), although no increase with age was seen for non-disabling back pain [4].

Even though chronic pain had a mean duration of approx. 10 years, around 10% recovered and 5% developed chronic pain during 2 years. The cumulative incidence rate of chronic pain was estimated to be 5.4% annually. However, it must be considered that by calculating cumulative incidence compared to incidence rate, the proportion of respondents who developed chronic was estimated without taking into account when during the timeframe this occurred. This may in fact have led to an underestimation of the true incidence. It is also possible that the groups of people that were characterized as “without pain” actually were people who had not had chronic pain, but may have had pain lasting less than 3 months. Previous prospective studies among older people are few and mostly pain-site-specific [4, 54, 79, 155]. For example, in a study among older adults with back pain, 20% developed chronic back pain after a mean of 3.6 years follow-up (estimated equivalent to incident rate of 5.5% annually) [4]. In contrast, in another population-based cohort study from the UK (n=2949, aged 50 +) the onset of widespread pain was 16.8% and 14.3% after three and six years respectively [155]. A more generalized pain population was investigated in a prospective study from the Netherlands including adults aged 55–85 years. During a three year period, 13.3% were found to have developed pain (equivalent to an annual incidence of approx. 4.3%) [54]. Higher incidence than in the present study, has also recently reported among elderly Singaporeans (mean age 68.9 years), where 20.1% developed chronic pain over two years (equivalent to an incidence rate of 10%) [79]. However, to the author’s knowledge the present study is the first presenting incidence rates in a European sample of older adults with non-site-specific pain with the novelty of also including of the oldest old. Despite long durations of pain and prevalence rates consistent over time, the results indicate that chronic pain is not a “steady state” in old age. The present results show incidence rates comparable to previous findings in younger populations, and that both onset and recovery from chronic pain seems to occur far into old age. Moreover the present result also offers generalizability regardless of the cause or site of the pain, which has a clinical implication because many older adults present with multiple pain sites or do not know the origin of their pain [3, 37].

Previous studies have shown that the number of pain locations is important for the impact of pain in old age and consequences such as sleep disturbances, ADL disability and mobility deficits, and increased psychological distress are found to be related to multiple sits of chronic pain among older adults [1, 47, 48]. In the present sample more than 38% reported more than one pain location and in the age group 85+ it was as many as 51.7%, indicating that they are at additional risk of an impact on daily life. The most common location for pain was back and lower extremities, and in concurrence with previous studies the proportion of those reporting pain in the lower extremities increased with age [79]. That pain location was measured by the response to an open question gave participants the opportunity to be specific in their answers but also meant a risk of diffuse responses. However, in the processing of data, it was found that this was not a problem.

The mean pain intensity at baseline was 3.22 on a 6-graded scale and varied only slightly over the different age strata (*paper I*), although the use of pain medications increased with age. It must, however, be noted that pain intensity was registered as "average pain intensity during the last week" and may thus, among these individuals (with, on average, a pain duration of 10 years), demonstrate temporal variation. Still, only a small increase in pain intensity between baseline and the 12-month follow-up was found in *paper III*.

In *paper I*, psychosocial dimensions of chronic pain, measured with the Multidimensional Pain Inventory (MPI), showed an increase with age for the dimensions pain severity, interference and affective distress, comparing the youngest stratum to the oldest. In a recent study among older women living alone (n=60, age ≥ 65 years) (using the same measure, MPI-S), a mean value of 1.8 was reported for affective distress [156]. Similarly, in a study among older adults with home assistants (n=295, aged 76–100), the mean score for affective distress was 1.5 [44]. The scores for affective distress in the present sample were thus slightly higher than in previous studies. A possible explanation for this could be that our sample may be assumed to be healthier people who live more active lives than previous samples that included patients requiring home assistance, and that the lives of the present sample hence were more affected by the pain. Life control, on the other hand, decreased with age, which may be explained by possible correlations both with increased pain severity as previously described, but also with the ageing process itself, including increased disease and smaller margins. This may also party explain the increased consumption of pain medications with age.

Kinesiophobia

Although the Cognitive Fear-Avoidance Model underlines the importance of considering kinesiophobia in chronic pain development in general populations[104], kinesiophobia had previously been poorly evaluated among older adults. Nor had the psychometric properties of the most commonly used measure for identifying kinesiophobia, namely the Tampa Scale of Kinesiophobia, been established among older adults. This advocated evaluation of kinesiophobia and further psychometric testing before its use in older populations. *Paper II* showed that the Swedish version of TSK-11 was a valid and reliable measure of kinesiophobia, with regard to construct validity, factor structure and test-retest reliability. Since the short 11-item version of TSK also offers the advantages of brevity, reducing administration time and patient burden compared to longer versions, it thus makes it more suitable for use among older adults compared to longer versions. However, some aspects concerning the construct of kinesiophobia need further contemplation. To begin with, it has previously been implied that the Tampa Scale of Kinesiophobia not only measures kinesiophobia but comprises some underlying constructs. For example, TSK-11 has been shown to consist of the two underlying constructs: somatic focus and activity avoidance [90, 119, 125, 157, 158]. This dimensionality was supported by the confirmatory factor analysis in *paper II*. However, although there were small statistical differences between the models (e.g. in goodness-of-fit tests and the magnitudes of the factor loadings) in favour of the two-factor solution, they were in practice largely equivalent. The interpretation of this result was that both TSK-AA and TSK-SF belong to the overlying kinesiophobia construct, but also are two clear underlying constructs. The clinical implication is that both the total score and the scores from the subscales may be used. However, the decision of which to use depends on whether the interest of the study lies in the underlying aspects of kinesiophobia (Somatic Focus and Activity Avoidance) or in assessing general levels of kinesiophobia. In a clinical perspective consideration of the subscales may be important for targeted treatment and the total score could be used advantageously for screening and identification of patients at risk.

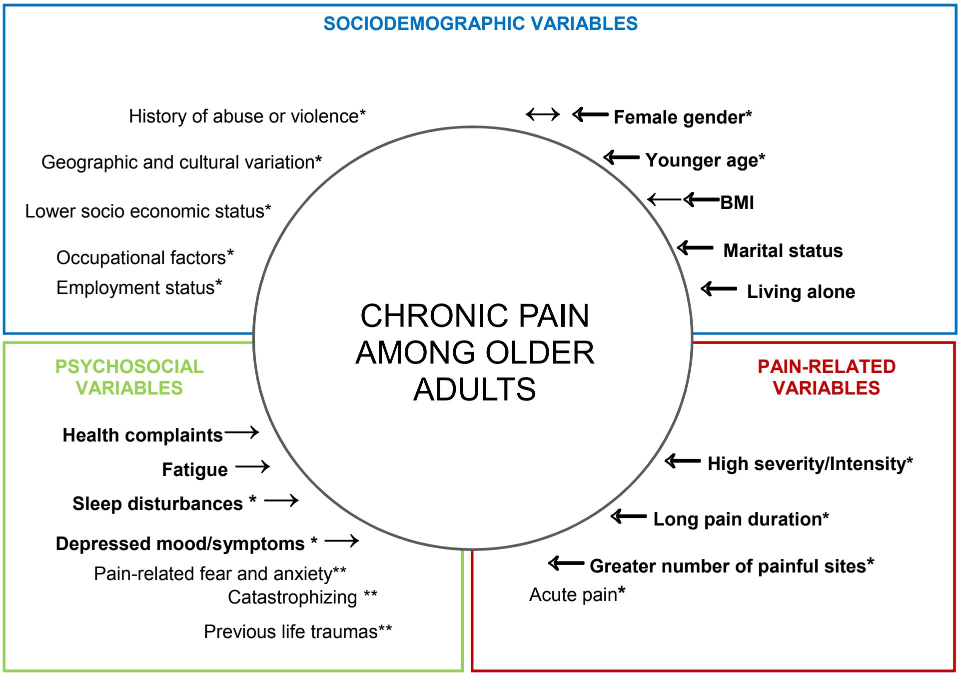
Secondly, when considering kinesiophobia, it is also essential to bear in mind that kinesiophobia is not a dichotomous characteristic; rather it is described as a syndrome which varies in degree [31]. To make this easier to relate to and to enable evaluation of its difficulty, a cut-off value can be helpful. For TSK-11, there was no pre-existing cut-off value differentiating between high and low kinesiophobia. However, for the original 17-item TSK, scores >37 have generally been considered as a high level of kinesiophobia [104]. When estimating this for TSK-11, by using the same proportion as used for the original version, it equalled to 35 out of 44 points.

As reported in *papers II and III*, the mean score of kinesiophobia at baseline was 22.8 and thus only a small proportion (i.e. the 90th percentile) reached beyond the limit for high kinesiophobia. These individuals were characterized as being frailer and predominantly living in care homes. In comparison to three previous studies among younger samples, using the 11-item version of the TSK [125, 158, 159] the levels of kinesiophobia reported in *paper III* were lower. However the present result corresponds with another study in a heterogeneous chronic pain sample where a subgroup aged 55–81 years were found to have lower levels of pain-related fear than middle-aged patients [82], indicating that the burden of high kinesiophobia may be lower among older adults than among younger people. *Paper III* adds to this result by also including those over the age of 81 years. In practice, this suggests that kinesiophobia might play a less significant role in chronic pain among older adults. A possible explanation could be a higher extent of stoic belief such as age-related reductions in negative emotions, declines in emotional expressivity, and increases in emotional control, which have been reported in relation to pain among older adults [160].

Another consideration was whether kinesiophobia is a construct that is stable over time. Woby et al., 2005, suggested in their study that a reduction of three points is needed to be 95% confident that a change has occurred [90]. With regard to *paper II*, this assumption would mean that a clinically relevant change of kinesiophobia occurred at individual level among 51.0% of the participants, and that both worsening (24.6%) and recovering (26.4%) from kinesiophobia occurred. However, on group level kinesiophobia was found to be relatively constant over time (at least over the period of one year) because no changes over time were seen when comparing the means of either of the subscales (i.e., TSK-AA and TSK-SF) or the total scale. So despite the identified individual variations, the presence of kinesiophobia among older adults does appear be constant at least over one year.

Related factors and their potential as possible predictors

The longitudinal design of the present study made identification of risk factors possible, although the high prevalence of chronic pain in previous studies indicates that a development of chronic pain over a two-year period would be likely. A two-year follow-up may seem like a relatively short period of time to detect changes in a chronic pain population. However, this timeframe was chosen in a first exploratory approach to identify possible indications of changes in the sample, and will hopefully encourage future studies with longer follow-up. In figure 5, the factors related to chronic pain in our sample are illustrated together with previously identified factors in older adults and in general populations. However, there are many complex relationships, and the multidimensionality of chronic pain makes it hard to establish direct linear relationships for any of the outcomes. Therefore, the interpretation and possible clinical implications of the identified variables are elaborated below.



Arrow= Illustrates relation to chronic pain in previous studies among older adults (→ Prediction, ↔ Association)
Bold arrow= Illustrates relation to chronic pain in this study (→ Prediction, ↔ Association)
* Variable predicting chronic pain in younger populations
** Variable associated with chronic pain in younger populations

Figure 5.
Variables related to chronic pain in the present sample, and in previous studies among older adults and younger adults.

Pain characteristics

Pain characteristics such as intensity, duration and number of sites with pain as predictors of chronic pain had not previously been explored in older adults, but were all identified as predictors of chronic pain in *paper II*. That pain characteristics seem to predict further pain problems has previously been shown in studies among younger populations [78, 161, 162]. The present findings in *paper II* add to this. In contrast, pain intensity was not identified as a predictor of either physical activity (*paper IV*) or kinesiophobia (*paper III*), which suggests that pain intensity may be more present in the establishment of pain behaviours than in its maintenance over time. However, based on our results, considerations of pain characteristics and in particular early measurements of pain intensity are crucial to detect severe pain. This is important for two reasons, first to optimize pain treatment but also as a preventive measure to identify those at risk of developing and maintaining future pain.

Demographic variables

A possible interpretation of younger age as a predictor of chronic pain onset may be that the onset of chronic pain is more likely to occur in younger age than among the most elderly. Older adults are also suggested to be less likely to report pain, especially pain of weak and mild intensity [33]. In this case it could mean under-reporting of the pain prevalence.

To explore possible gender differences in chronic pain was not the scope of this thesis. However, bearing in mind that female sex is an established risk factor for chronic pain in general populations [78] and that the prevalence of chronic pain is often reported to be higher among women also in older populations [1, 35], it must hence be considered as a possible confounder also among older adults. In *paper II*, the final regression model for chronic pain persistence was repeated separately for women and men, but, no risk factor then remained significant for men. This could indicate that the identified predictors are only valid for women and that the causality thus might differ for men, but may also have been influenced by the distribution in the two groups. Sex differences were also identified for activity level in the total sample in *paper IV*, where men reported higher levels of physical activity ($p< 0.01$). However, no differences between sexes in physical activity levels were found among those suffering from chronic pain.

Obesity is common in old age [163] and shares may comorbidities with chronic pain such as depression and disability. Many chronic pain conditions common in old age such as osteoarthritis and back pain are also related to overweight, e.g. due to increased pressure on the joints. Despite this, obesity in relation to chronic pain is poorly studied among older adults. However, in a representative community based sample of older adults (n=840, aged $\geq$70) those with a BMI 30–34.9 were twice as likely (OR=2.1, 95%CI=1.33–3.28) to have chronic pain and for those with a BMI >35 (severe obesity) the odds ratio almost doubled (OR=4.5, 95% CI=1.85–12.63) [164]. In contrast, no difference regarding BMI could be found between the respondents with chronic pain compared to those without chronic pain (27.26 vs. 26.44, p=0.20) in *paper IV*. Interestingly, lower BMI was found to be related to persisting pain at the 12-month follow-up (OR=0.89, 95% CI=0.79–0.99) in *paper I* and lower BMI was also was also was associated with baseline physical activity (OR=0.92, 95% CI=0.85–0.96) but not predictive of reaching sufficient physical activity levels at follow-up (*paper IV)*. There are no logical explanations for the reverse relation to BMI in our results. It is possible that the result would have been different if the variable BMI had been divided into several groups.

Psychosocial variables

In contrast to the pain characteristics (intensity, duration and locations), no psychosocial variables were identified as predictors of future chronic pain. This applies to the MPI dimensions as well as to depressed mood. In relation to general populations where psychosocial aspects have been identified as predicting both onset and maintenance of chronic pain [165-168], it seems as if this might not be the case in older adults. Instead it seems as if that pain characteristics play a more significant role in chronic pain development among older adults. Surprisingly, depressed mood was not associated with kinesiophobia (*paper III*). The lack of associations with depressed mood could be explained by older adults expecting pain as well as lower activity (i.e. as a part of ageing) and therefore employing different mechanisms for dealing with the pain (i.e. taking medication or ignoring the pain). There are also several challenges related to identifying depressive symptoms among older adults. Depressed older adults are found to report somatic complaints such as pain and describe non-specific symptoms (i.e. irritability, insomnia, decreased energy, difficulty concentrating, and memory problems) rather than reporting depressive symptoms [169].

Increasing attention has also been given to self-efficacy in explaining pain and pain disability [93, 170, 171]. Self-efficacy has also been suggested to mediate pain-related fear and avoidance behaviours in the Fear-Avoidance Model [93], a mediating effect that may be dependent on the level of self-efficacy, i.e., when self-efficacy is high, elevated pain-related fear does not lead to greater pain and disability. But where self-efficacy is low, elevated pain-related fear is more likely to lead to greater pain and disability [93]. The role of self-efficacy was explored in *paper IV* and *paper III,* where it was found to be associated with baseline physical activity levels, and baseline kinesiophobia. In contrast to previous findings, the association of self-efficacy found at baseline did not remain significant in the multiple regression analysis in either of the studies. It is possible that a more context-specific measure of pain-related self-efficacy might have shown a greater impact on the outcomes than detected by the General Self-Efficacy Scale. This needs further investigation.

Another cognitive aspect that was previously found to be associated with the occurrence of chronic pain among older adults is self-perception of health [4, 172, 173]. In a survey conducted in Finland, the proportions of participants who reported poor or fair health increased with both frequency and intensity of pain (n=4542, aged 15–74 years), and chronic pain was found to be independently associated with poor self-perceived health, regardless of chronic diseases, gender or age [173]. In another cross-sectional population-based study from Brazil the occurrence of pain among older adults (n=872, age $\geq$ 60 years) was associated with a worse self-perception of pain (OR=4.2 95% CI 2.5–7.0) [172]. Self-rated health as a predictor of chronic pain was also considered among older adults with back pain in the paper by Docking et al., which showed that those reporting poor health at baseline had almost a 4-fold increase (RR=3.8; 95% CI 1.8–8.0) in the reporting of back pain onset at follow-up compared to those who had previously reported very good health [4]. In *paper IV,* participants with chronic pain reported worse health than respondents without chronic pain. The perception of health was also found to worsen between baseline and 12-month follow-up in the chronic pain sample *(paper IV).* Poor self-perceived health was also identified as a predictor of kinesiophobia in *paper III*, but did not predict physical activity levels among those with chronic pain at the 12-month follow-up (*paper IV*). The relation between poor health and kinesiophobia is not unexpected given that pain itself may be regarded as a health factor, and is found to be strongly associated with other pain-related variables [172]. Poor self-perceived health has also been found to relate to poor recovery from chronic pain [50]. However, the result indicates that the contribution of health perceptions merits further investigation among elderly populations.

Impact on physical activity

The impact of chronic pain and kinesiophobia on physical activity levels (*papers II and IV*) was substantial and confirms studies previously performed among older adults with chronic back pain [106, 174]. As mentioned above, the fear-avoidance model implies that daily activities and functional capacity may be reduced to avoid pain. Hence, untreated pain may lead to a negative spiral with the following: increased fear of movement, avoidance behaviour and ultimately disuse, disability, depression and further exacerbation of chronic pain [8, 104]. Disability is thus one of the core constructs in the Cognitive Fear-Avoidance Model, but the content of the disability dimension has been poorly defined within the model and hence a large variety of disability measures have been used (both general and condition-specific) [72]. Pain-related disability can be seen as an umbrella concept, which includes a variety of underlying domains, such as physical activity.

As declining physical activity frequently occurs when one ages, the elderly may be especially susceptible to becoming victims of a fear avoidance of pain cycle. In *paper IV*, kinesiophobia was found to be related to physical activity, an association that remained even when controlled for age, gender and baseline physical activity. Previous studies conducted among general populations have suggested that fear-avoidance beliefs are associated with mechanisms type such as type of activity, and not specifically with the amount or level of physical activity [99, 105, 106]. A similar argument have been made by Leeuw et al. (2007) who hypothesize that patients are more likely avoid the kinds of activities that they believe are related to an increased risk of pain and (re)injury rather than lessening all types of physical activity [175]. However, a possible explanation for the contradictory result in *paper II* may be increased feelings of frailty and more severe consequences of a possible injury in old age. For example, a recent study identified avoidance of activities due to fear of falling as an important contributor to sedentary behaviour among older adults with chronic musculoskeletal pain [176]. In a similar way, Bishop et al. argue that there is an increased risk of acute pain becoming chronic if the older adult thinks that a decrease in physical and social activities is a natural part of ageing [177]. In the end, it is thus difficult to know whether inactivity is a cause or a consequence of chronic pain. However, the occurrence of kinesiophobia seems to play a significant role for physical activity levels, so targeting kinesiophobia could prove beneficial in improving both chronic pain and physical activity levels in this group. Ability to measure kinesiophobia among older adults in a valid way is a step on the road, and effective and well-targeted interventions another. Interventions targeted at reducing fear-avoidance beliefs (e.g. cognitive-behavioural therapies) such as exposure in vivo, have shown positive effects regarding both disability and the experience of pain in younger populations [178]. Whether the same interventions also have an effect on physical activity among older adults needs further investigation, but encouraging results were recently presented in a pilot study (including older adults with chronic low back pain), where graded exposure-based active physical therapy showed significant effects in physical activity, pain intensity and fear-avoidance beliefs with effect sizes ranging between 0.91 and 1.37 [179].

Conclusions and clinical implications

The fact that 38.5 per cent in this population-based sample experienced chronic pain shows a large unmet need for pain management among older adults and presents a major policy challenge. To address the burden of chronic pain among older adults, the findings of this thesis highlight the importance of pain characteristics such as intensity/severity, duration and number of locations, rather than age-related symptoms and psychosocial variables. This is important for two reasons, first to optimize pain management, and second, as a preventive measure to identify those at risk of developing and maintaining future pain.

The 11-item version of the Tampa Scale of Kinesiophobia can be recommended as a valid and reliable measure for capturing kinesiophobia among older adults. The total score as well as the subscales may be used, depending on whether the interest lies in treatment management or in screening/identification of patients at risk.

Although generally low levels of kinesiophobia were found among those with chronic pain, a clinically relevant change of kinesiophobia occurred among 51.0% of the participants, indicating that both worsening (24.6%) and recovering (26.4%)

from kinesiophobia occurs in old age. Poor self-perceived health and high pain intensity were associated with kinesiophobia, and attention to these characteristics will help clinicians in identifying who is most likely to suffer from high kinesiophobia. The results indicate that potential interventions regarding kinesiophobia should aim to decrease pain intensity and strengthen these individuals' health beliefs.

The findings also highlight that older adults with chronic pain are at higher risk of functional decline and additional chronic diseases, due to significantly lower levels of physical activity compared to older people without chronic pain. It was found that kinesiophobia played an important role in predicting future physical activity levels and hence should be considered when aiming at increasing physical activity levels among older adults with chronic pain.

Areas for further research

- The low explained variance in the predicting models means that other factors are likely to affect kinesiophobia among older adults. To further explore this and to fully understand the impact of chronic pain among older adults, qualitative methods should be used in order to illuminate other possible predictors of further quantitative testing in future multidimensional models.
- Some of the constructs included in the Cognitive Fear-Avoidance Model were investigated in this thesis; to fully explore the validity of the model among older adults future studies are needed that include all related constructs in a multidimensional model.
- As interventions targeted to reduce kinesiophobia (e.g. cognitive-behavioural therapies) have shown positive effects regarding both disability and the experience of pain in younger populations, studies investigating whether the same interventions also have an effect among older adults are greatly needed.
- As our results indicated that the predictors of chronic pain persistence were only valid for women and that the causality thus might differ for men, this is an important aspect that needs to be considered and further investigated.

Summary in Swedish

Med stigande ålder löper äldre en ökad risk för att utveckla hälsotillstånd som orsakar smärta och som en konsekvens lever många äldre med långvarig smärta. Den långvariga smärtan påverkar många aspekter av livet och i tidigare studier bland äldre rapporteras ofta symtom såsom; sömnproblem, depression, nedsatt funktionsförmåga och låg livskvalitet vara relaterat till långvarig smärta. Långvarig smärta kan därför ses som ett viktigt folkhälsoproblem. Den aktuella förändringen i åldersstrukturen i vårt samhälle innebär också att i planeringen av framtida hälso- och sjukvård, måste allt större hänsyn tas till behovet av en åldrande befolkning. Detta ställer således höga krav på kunskap om hur långvarig smärta utvecklas i den äldre befolkningen. Men trots att smärta är vanligt bland äldre är vården och behandlingen av äldre med långvarigsmärta ofta otillfredsställande. En orsak till detta kan vara attityder kring smärta både hos de äldre själva och hos vårdpersonal. En annan orsak kan vara att kunskapen om smärtans uppkomst och utlösande faktorer samt hur dessa interagerar med varandra i förhållande till smärtan fortfarande är mycket sparsam bland äldre, speciellt bland de allra äldsta. Tidigare kunskaper om långvarig smärta bland äldre har i huvudsak baserats på resultat från tvärsnittsstudier, på studiegrupper i specifika vårdmiljöer, eller särskilda patientgrupper och en mer generell kunskap behövs därför.

Kinesiofobi (rädsla för rörelse på grund av smärta) har visat sig bidra till utvecklande av långvarig smärta och depression bland yngre individer och tros även vara en viktig länk mellan smärta och nedsatt funktionsförmåga och minskade aktivitetsnivåer. Det saknas i dag studier som har studerat dessa samband bland äldre och de instrument som finns för att identifiera kinesiofobi har inte tidigare utvärderats för äldre personer. På grund av detta saknas det kunskap om hur kinesiofobi påverkar utvecklingen av smärta bland just äldre. Ökad kunskap kring kinesiofobi bland äldre är därför av stor betydelse eftersom kinesiofobi skulle kunna bidra till vidmakthållandet av smärta, men även till minskade nivåer av fysisk aktivitet, vilket i sin tur ytterligare ökar risken för ohälsa bland äldre.

Om smärtupplevelsen inte skulle skilja mellan äldre och yngre individer, skulle det vara möjligt att generalisera kunskaper från yngre populationer till äldre. Men forskning tyder på att åldersrelaterade förändringar påverkar smärtupplevelsen och att vissa faktorer relaterade till smärta troligen fungerar på ett något annorlunda sätt vid högre ålder. Detta skulle innebära att de faktorer som bidrar till utvecklande och vidmakthållande av långvarig smärta troligen skiljer sig mellan äldre och yngre individer och att åtgärder således bör inriktas på olika sätt beroende på ålder. Även detta stöder behovet av ytterligare kunskap kring långvarig smärta bland äldre. För att öka kunskapen och bidra till ökad generaliserbarhet av resultaten, måste den långvariga smärtan och dess relaterade faktorer undersökas longitudinellt och brett, det vill säga oavsett bakomliggande orsak till smärtan eller beroende på var smärtan är lokaliserad i kroppen. Sådan kunskap skulle kunna bidra till forskningsområdet genom att öka förståelsen för utvecklingen av långvarig smärta och dess konsekvenser bland äldre. Ökad kunskap om smärta hos äldre skulle också göra det lättare att identifiera riskindivider, lättare att prioritera och underlätta preventivt arbete. Detta skulle i förlängningen innebära bättre vård och behandling av äldre med långvarig smärta och bidra till förbättrad hälsa och livskvalitet i den äldre befolkningen.

Det övergripande syftet för avhandlingen var att studera förekomst, utveckling och faktorer relaterade till långvarig smärta och kinesiofobi bland äldre, samt hur dessa påverkar graden av fysisk aktivitet. Avhandlingen består av fyra delstudier där studie II är en psykometrisk studie och de övriga tre populationsstudier (studie 1I, III-IV). All fyra delstudierna har baserats på samma material och data har erhållits genom postenkäter som samlades in vid baslinjen, efter 12 och 24 månader, under 2011-2013. Deltagarna (N = 2000) valdes ut genom ett obundet randomiserat urval från Svenska Post och Adress registret (SPAR). Urvalsramen var hela svenska befolkningen i åldern 65 år och äldre.

Totalt 1141 individer, i åldrarna 65-103 år, svarade vid det första enkät utskicket. Svarsfrekvensen var 57.8 %. En bortfallsanalys av deltagarna, indelad i tre åldersstrata (65-74, 75-84, 85+), visade inga skillnader avseende kön eller ålder jämfört med urvalet eller den totala svenska befolkningen. Vid 12-månadersuppföljningen inkom totalt 782 (88.4%) enkäter. För att öka svarsfrekvensen till 24-månadersuppföljningen, sändes återigen frågeformulär till alla deltagare som svarat vid baslinjen och 843 (81.2 %) svarade då på den sista enkäten. När bortfallet över tid analyserades visade det sig att de deltagare som fallit bort mellan uppföljningarna var något äldre och i större utsträckning boende på särskilt boende eller änka/änkling, jämfört med de som svarade.

I den första delstudien, studerades prevalens, kumulativ incidens och utveckling av långvarig smärta över tid (två år). För att identifiera faktorer relaterade till utveckling och vidmakthållande av långvarig smärta användes logistiska regressionsanalyser. Resultaten visade att 38,5% av deltagarna rapporterade långvarig smärta. Långvarig smärta var vanligare bland kvinnor och förekomsten steg för de över 85 år. Den kumulativa incidensen beräknades till 5,4 %. Även om långvarig smärta var vanligt förekommande visade resultaten att både tillfrisknade och insjuknade skedde under två års tid. Att vara kvinna, ha lägre BMI, hög smärtintensitet, lång duration och smärta på mer än ställe i kunde predicera att smärtan kvarstod. Det faktum att nästan två av fem i denna populationsbaserade studie rapporterade långvarig smärta belyser ett stort otillfredsställt behov av smärtlindring bland äldre. Resultaten från regressionsanalyserna visade även att smärtans intensitet, duration och multipla smärtlokalisationer spelade en större roll för att smärtan skulle kvarstå, jämfört med åldersrelaterade symptom och psykosociala variabler, vilka ofta rapporterats bidra till långvarig smärta bland yngre. Denna kunskap kan användas för att optimera smärtlindring men också i rent preventivt syfte för att identifiera äldre personer i risk för att utveckla långvarig smärta.

Delstudie II, var en psykometrisk utvärdering av Tampa skalan för Kinesiofobi (TSK-11). Begreppsvaliditet utvärderades avseende ”korrigerade item - total korrelationer” och konvergent validitet. Faktorstruktur testades genom konfirmatorisk faktoranalys. Reliabilitet analyserades avseende intern konsistens (Cronbach´s α) och rest-re test stabilitet (ICC och viktad Kappa). Bevis på konvergent validitet gavs av signifikanta positiva korrelationer med ADL-trappan (r=0.20) och smärtintensitet (r=0.31) samt en signifikant negativ korrelation med fysisk aktivitet (r= -0.38). Den konfirmatoriska faktoranalysen visade att både en- och två faktorlösningar var möjliga. Cronbachs α koefficienterna varierade mellan 0.74 och 0.87. Test-retest analyserna visade stark överensstämmelse avseende ICC (r=0.75, 95 % CI 0.64 -0.82) samtidigt som de viktade k koefficienterna var svaga till moderata. Sammantaget visade resultaten att den svenska versionen av TSK-11 hade acceptabel begreppsvaliditet, faktorstruktur, och reliabilitet och därmed kan anses vara lämplig för äldre personer med långvarig smärta. Den totala poängsumman samt delskalorna kan användas, beroende på om intresse ligger i behandling eller för screening/identifiering av patienter som löper risk för hög grad av kinesiofobi.

I delstudie III, studerades förekomst och utveckling av kinesiofobi under en 12-månaders period. Vidare studerades även relationen mellan kinesiofobi, smärtans karaktärer och kognitiva/emotionella variabler (dvs. tilltro till sin förmåga, nedstämdhet och hälsa). Även om i allmänhet låga nivåer av kinesiofobi rapporterades bland de med långvarig smärta, identifierades en kliniskt relevant förändring i kinesiofobi över tid av bland en majoritet av deltagarna, vilket tyder på att både försämring och förbättring skedde under ett års tid. Tio procent rapporterade även nivåer som anses som hög grad av kinesiofobi, hög grad av kinesiofobi var vanligare bland sköra äldre boende på särskilt boende. Dålig självupplevd hälsa och hög smärtintensitet var också associerade med kinesiofobi och sammantaget bör dessa faktorer uppmärksammas för att möjliggöra identifiering av individer som är mest sannolika att drabbas av hög grad av kinesiofobi. Resultaten belyser att om man vill minska graden av kinesiofobi bland äldre så bör man inrikta sig på att minska den äldre personens smärtintensitet och arbeta för att stärka dessa individers självupplevda hälsa.

I delstudie IV, studerades graden av fysisk aktivitet i relation till långvarig smärta. Resultaten visade att bara 31.1 % av de äldre med långvarig smärta nådde upp till de nivåer av fysisk aktivitet som rekommenderas för äldre av bland annat WHO. Bland deltagare utan långvarig smärta var motsvarande andel 56.9 %. Detta innebär i förlängningen att äldre med långvarig smärta löper en betydligt större risk för nedsatt funktionsförmåga och ytterligare kroniska sjukdomar, jämfört med äldre utan långvarig smärta. Kinesiofobi visade sig spela en viktig roll i att förutsäga framtida nivåer av fysisk aktivitet, även när resultaten kontrollerades för tidigare aktivitet och smärtans intensitet. Interventioner som syftar till att öka den fysiska aktivitetsgraden bland äldre med långvarigsmärta bör därför även beakta kinesiofobi.

Sammanfattningsvis, även om långvarig smärta var ofta mycket utbrett och ihållande, visade resultaten att deltagarna i studien både utvecklade och tillfrisknade från sin långvariga smärta under studiens gång. Iakttagelserna markerar betydelsen av tidig smärtlindring i förebyggandet framtida smärta bland äldre. Det måste också beaktas att äldre vuxna med kronisk smärta löper större risk för funktionell nedgång och ytterligare kroniska sjukdomar, på grund av betydligt lägre nivåer av fysisk aktivitet jämfört med äldre utan lågvarig smärta. Kinesiofobi bland äldre kan fångas upp av TSK-11 och spelar en viktig roll när det gäller att förutsäga framtida fysiska aktivitetsnivåer. Interventioner mot kinesiofobi har således tydliga (folk-) hälsoeffekter och studien belyser därför vikten av att både mäta/utvärdera samt behandla kinesiofobi bland äldre med långvarig smärta.

Acknowledgements

Den här avhandingen har genomförts vid Centrum för Primärvårdsforskning vid Medicinska fakulteten, Lunds Universitet. Jag vill på denna sida rikta ett stort tack till alla som hjälpt mig genom mina studier under doktorandperioden. Ett speciellt tack vill jag rikta till:

Alla deltagarna i studien, utan ert engagemang att svara på tusentals enkäter, hade denna avhandling aldrig varit möjlig att genomföra!

Min huvudhandledare Professor *Ulf Jakobsson,* för din otvivelaktiga tilltro till min förmåga och för ditt tålamod med mina miljontals frågor. Jag har lärt mig så mycket av dig och det är jag verkligen oerhört tacksam för!

Docent *Eva Ekvall-Hansson* och Professor *Kristina Sundquist,* bihandledare och medförfattare, för att ni alltid tagit er tid då jag behövt, för konstruktiv kritik på mina manus och kappa! För många kloka ord och råd på vägen! Jag är mycket glad över det stöd jag fått under hela min doktorandperiod.

Professor*, Jan Sundquist,* för att du gjorde det möjligt för mig att vara en del av den kreativa miljön på CPF. Jag vill inte sluta ☺

Per Condelius, för all den tid och noggrannhet du bidrog med vid datainsamling och inmatning av enkäter. Vilket kaos det skulle ha blivit bland ettor och nollor utan Dig!

Steve Gilliver och *Patrick Reilly* för noggrann översyn av språket i flera av mina manuskript och *Karolina Englund* för hjälp med datainmatning.

Alla *doktorander* och *seminarieledare* i forskargruppen Äldres hälsa och personcentrerad vård, Institutionen för Hälsovetenskaper, Lunds Universitet, för att ni har manglat mina manus och för att ni bidragit till en mycket värdeful del av min doktorandutbildning.

Ulrika Möller Olsson, allierad sjukgymnast/fysioterapeut kollega och vän, för uppmuntrade heja rop och stöd under hela min doktorandperiod! Och ett speciellt tack för att du tog dig tid att läsa min kappa, när den och dess kapten definitivt höll på att gå på grund!

Mina kollegor på VC Granen som stöttat mig under hela tiden!

Alla mina vänner och kollegor på Centrum för Primärvårdsforskning och speciellt till *Karolina Palmer*, *Henrik Olsson*, *Emelie Stenman*, *Klas Cederin* och *Bertil Kjellberg* för att ni alltid ställt upp och hjälpt mig med allt från statistikproblem, IT-krångel, kattvakt, publiceringsstrul och skrivkramp! Bättre kan man inte ha det!

Sara Larsson Lönn, för daglig uppmuntran och samtal. Litet om vetenskap och mycket om livet.

Helene Rosenquist för vänskap och allt roligt som händer kring dig. Och verkligen för all möjlig hjälp med stort och smått, ofta i senaste minuten.

Mina svärföräldrar *Ann-Kristin* and *Arne* för stort stöd till vår lilla familj under en hektisk sommar av "kappa-skrivande".

Till min familj, *Frida & Maja* för att ni alltid finns där och till *Mazdak Tavoly*, för alla insiktsfulla kommentarer på mina manus och intressanta diskussioner kring forskning. Och speciellt till *Mamma* och *Pappa* för allt, min trygghet och min kompassriktning i livet!

Till min kära *Martin* för din tro på min förmåga att lösa det mesta och för att du alltid, och allt som oftast, räddar mig i nöden på vägen dit. Tack för ditt stöd, markarbete och stora tålamod!

Denna avhandling har genomförts med finansiellt stöd från Gustav V och Drottning Victorias Frimurarestiftelse, den Gyllenstiernska Kapperupstiftelsen, och Ragnhild och Einar Lundström's Stiftelse.

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Printed by Media-Tryck, Lund University 2016 Nordic Ecolabel 3041 0903

The context in which painful symptoms are processed and the meaning attributed to them are recognized as important factors in shaping the pain experience.

Melzack, 1973

LUND UNIVERSITY
Faculty of Medicine

Lund University, Faculty of Medicine
Doctoral Dissertation Series 2016:78
ISBN 978-91-7619-304-4
ISSN 1652-8220

9 789176 193044