Assessment of Pain in Patients with Dementia

Development of a Staff-Administered Behavioural Pain Assessment Tool

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Dissertation for the degree of philosophiae doctor (PhD)

University of Bergen

2008

UNIVERSITY OF BERGEN

ISBN 978-82-308-0601-2
Bergen, Norway 2008

Printed by Allkopi Tel: +47 55 54 49 40

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ACKNOWLEDGEMENTS

The studies in this thesis were inspired by my work as a palliative care and nursing home physician at the Red Cross Nursing Home, Bergen from 1997. During my work with patients, relatives, health care professionals and my colleagues, I found it most interesting and important to focus on research into the elderly and nursing home medicine, and to explore the issue of pain in patients with dementia.

I would like to express my sincere gratitude and thanks to the following persons:

My supervisor, Professor Anne Elisabeth Ljunggren of the Department of Public Health and Primary Health Care, Section for Physiotherapy Science, who believed in the potency of the project, and gave me an opportunity to learn the research process. With her outstanding generosity and wisdom, she gave me confidence, encouraged me to continue and supported our work on the weakest of the elderly. Professor Ljunggren's patient and competent guidance was most valuable. Most of all, the way she communicated with me as a research fellow was an important learning step that I will take with me in future tasks.

My co-supervisor, Associate Professor Liv Inger Strand of the Department of Public Health and Primary Health Care, Section for Physiotherapy Science, provided important support in developing the methods used in the thesis. Her great skill in writing articles and her perseverance with our cooperation was a substantial contribution to my work and learning process. Dr Strand deserves great thanks for the patience and support she displayed in this process, focusing as she did on the main findings and always sticking to the point during the many hours I spent in her office.

Professor Rolf Moe-Nilssen of the Department of Public Health and Primary Health Care, Section for Physiotherapy Science, provided outstanding support in connection with all statistical matters and he also gave important advice during testing of the psychometric properties of the newly developed questionnaire. His good humour, talk about physical activities and laughter in 'serious situations' gave me a new perspective.

Professor Dag Aarsland of the Department of Clinical Medicine at the University of Bergen helped me to see this project through to completion. His outstanding competence in research and dementia and his international research network opened perspectives for my further research.

Professor Andrea Lynn Snow of the University of Alabama, Centre for Mental Health and Ageing, my good friend and close collaborator at the start of the project. With her great

experience of research into dementia and care for the elderly, she has been a good adviser and discussion partner, helping to provide an international perspective on my scientific work.

Åse Sivertsen, PhD and Astrid Lunde, PhD, are my beautiful friends at the Department of Public Health and Primary Health Care. Thank you for sharing the same fate as me and coffee and a laugh during breaks.

The patients, their relatives and their caregivers at the Red Cross Nursing Home, Bergen who participated in this study were the basis for data collection. The physicians and about 120 caregivers supported my work with great interest and competence, and they gave priority to our education programme and data collection in an exemplary manner. Without their goodwill and help it would have been difficult to complete this thesis. Special thanks are due to Alfhild Karlsen for her excellent organisation of the data collection. The directors of Bergen Red Cross Nursing Home, Britt Hysing-Dahl and Elin Sjursen, gave me great support, as did Helga Lorentzen. Thanks also to Trond Bentsen of the Faculty of Dentistry, Audiovisual Section, at the University of Bergen, who produced the video recordings, and Aase Huus, who designed the MOBID and MOBID-2 questionnaire. It was most interesting and instructive for me to join them in this development process.

The work presented in this thesis was carried out between 2004 and 2008. The Norwegian Foundation for Health and Rehabilitation supported the study financially. Grants were also provided by Kavli's Dementia Research Centre, Bergen.

Thanks also to my former chef, Professor Eberhard Klaschik of the Department of Anaesthesiology, Intensive Care, Pain Therapy and Palliative Medicine at the Malteser Hospital, University of Bonn. Under his outstanding guidance, I learned much about the nature of pain, ethical decision making, and communication. This work was an important prerequisite for understanding the needs of the weakest elderly.

Finally, I would like to mention my beautiful family. My parents, Dr. Phil. Günter and Mechtild Sandgathe, gave me all their attention, support and strength, and not only during my work on this project. The death of my mother during this period taught me a great deal about love and responsibility as a daughter.

Special deep thanks to my best friend and partner, my husband and supervisor Stein Børge Husebø. In recent years, he has focused strongly on the needs of the elderly for palliative care. He provided great support in connection with the grant and the progress of the project, and he contributed as a highly skilled pain therapist and palliative care physician with

remarkable wisdom and reflections. Most of all, he is my source of strength, both when I am exhausted and when I am in high spirits.

Last, but not least, I want to give six big hugs to our wonderful children, Maximilian, Elena, Lucas, Bjørn, Solveig and Ralf, who followed and supported my work with great interest, tolerance and understanding, offering beautiful comments along the way: ‘Poor mum!’ or ‘Stay with it, you can make it!’ You gave me feedback and trust, and assured me that you were not harmed during these years. On the contrary, I felt that you were proud to be a part of this, to me, important project.

Bergen, February 2008

LIST OF PAPERS

1. Husebo BS, Strand LI, Moe-Nilssen R, Husebo SB, Snow AL, Ljunggren AE. Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale (MOBID): Development and validation of a nurse-administered pain assessment tool for use in dementia. *J Pain Sympt Manage* 2007; 34:67-80.

2. Husebo BS, Strand LI, Moe-Nilssen R, Husebo SB, Ljunggren AE. Pain behaviour and pain intensity in older persons with severe dementia: Reliability of the MOBID Pain Scale by video uptake. *J Scand Caring Sci* 2008; in press.

3. Husebo BS, Strand LI, Moe-Nilssen R, Husebo SB, Ljunggren AE. Pain in older persons with severe dementia. Psychometric properties of the Mobilization–Observation–Behavior–Intensity–Dementia (MOBID-2) Pain Scale in a clinical setting. Under review.

4. Husebo BS, Strand LI, Moe-Nilssen R, Husebo SB, Aarsland D, Ljunggren AE. Who suffer most? Dementia and pain in nursing home patients: A cross-sectional study. *J Am Med Dir Assoc* 2008; in press.

ABBREVIATIONS

AD	Alzheimer's disease
ADL	Activities of Daily Living
ADVaD	Alzheimer's Disease & Vascular Dementia (Mixed dementia)
BPSD	Behavioural and Psychiatric Disturbances
cCT	Cerebral Computer Tomography
CDR	Clinical Dementia Rating
CI	Cognitive Impairment
DLB	Lewy Body Diseases
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders
fMRI	functional Magnetic Resonance Imaging
FTD	Frontotemporal Dementia
ICD-10	International Classification of Diseases - 10^{th} version
LPN	Licensed Practical Nurse
MMSE	Mini-Mental State Examination
MOBID	Mobilization-Observation-Behaviour-Intensity-Dementia
MOBID-2	Mobilization-Observation-Behaviour-Intensity-Dementia Parts 1 and 2
MOBID-b	MOBID bedside
MOBID-v	MOBID video recording
NH	Nursing Home
NRS	10-point Numeric Rating Scale
RN	Registered Nurse
SCI	Severe Cognitive Impairment
VaD	Vascular Dementia
WHO I-III	World Health Organisation's analgesic ladder

ABSTRACT

Aims

The aim of this thesis is to develop a staff-administered behavioural pain assessment tool for older persons with dementia, to test the instrument with respect to reliability and validity, and to use it in the clinical setting of an entire nursing home (NH) population.

Methods

In **Paper I**, the development of the Mobilization-Observation-Behaviour-Intensity-Dementia (MOBID) Pain Scale was described. In MOBID, the assessment of inferred pain intensity was based on the patient's pain behaviour in connection with standardized, active guided movements of different body parts. The internal consistency and inter-rater reliability of pain behaviour indicators and pain intensity scores were tested through bedside investigation and video recordings of 26 patients with severe dementia. Face validity was discussed by a focus group. Different aspects of construct validity were investigated.

Paper II documented the extended testing of the intra-rater and inter-rater reliability of the pain behaviour indicators and pain intensity scores of the MOBID Pain Scale by three external raters, using video recordings, concurrently and independently on days 1, 4 and 8.

In order to also assess pain from internal organs, the head and skin, an extended instrument, the MOBID-2 Pain Scale, was presented in **Paper III**. It comprised the original MOBID, renamed MOBID-2 Part 1, and MOBID-2 Part 2, which registered pain behaviour related to internal organs, the head and skin. Monitored over time, caregivers' observations were registered on pain drawings and inferred into pain intensity. Finally, overall pain intensity was assessed, including all observations registered in Parts 1 and 2. The internal consistency of the comprehensive MOBID-2 was examined for 77 patients. Furthermore, the inter-rater and test-retest reliability of pain behaviour indicators, pain drawings and pain intensity scores were tested. Arguments for face, construct and concurrent validity were added when pain scores from nurses using MOBID-2 were correlated with physicians' clinical examinations and other pain variables.

Paper IV was a cross-sectional study exploring the relationship between severity and diagnoses of dementia and the use of pain medication and other parameters of pain measured using pain intensity scores from MOBID-2 in 181 NH patients.

Results

The results of **Paper I** suggested that registration of pain behaviour indicators during standardised movements, as measured by the MOBID, can be used reliably to disclose pain intensity inferred by nurses in elderly persons with dementia. Internal consistency of the MOBID items was found to be high (α=0.90). The inter-rater reliability of inferred pain intensity scores was high to excellent (ICC=0.70-0.96), but varied between poor to excellent for individual pain behaviour indicators (κ=0.05-0.84). Arguments for construct validity were indicated, as the MOBID Pain Scale revealed significantly more pain than did pain scores during regular morning care. Video observation demonstrated higher pain intensity than bedside scoring. The pain intensity scores were highly correlated with the number of observed pain behaviour indicators. Finally, the overall pain intensity score was more associated with the highest pain score among the test items than with the mean score of all items.

As demonstrated by **Paper II**, facial expression of pain was most commonly observed, followed by pain noises and defence. Using video recording, inter-rater reliability was highest for pain noises, followed by defence, and facial expression (κ=0.44-0.92, κ=0.10-0.76, and κ=0.05-0.76, respectively, on day 8). Of the movements, mobilisation of arms and legs was rated most painful. The intra-rater and inter-rater reliability of the overall pain intensity scores was very good, ICC(1,1) ranging from 0.92 to 0.97 and 0.94 to 0.96, respectively. As opposed to observed pain behaviour, the reliability of pain intensity scores tended to increase on repeated assessment. It was suggested that the overall pain score was based more on interpretation of the most pain provoking movement during assessment than on the total number of observed pain behaviour indicators.

Using the MOBID-2 Pain Scale, the prevalence of any pain in patients with severe dementia was 81%, with predominance in the musculoskeletal system, as demonstrated in **Paper III**. Most frequent and painful was mobilising of the legs and arms (Part 1). Pain in the pelvis and/or genital organs was frequently observed in MOBID-2 Part 2. The internal consistency of the whole scale was highly satisfactory (α=0.82-0.84). Moderate to excellent inter-rater

and test-retest reliability was demonstrated for pain behaviour indicators (κ=0.44-0.90 and κ=0.41-0.83) and pain drawings (κ=0.46-0.80 and κ=0.48-0.93). Moderate to excellent inter-rater and test-retest reliability (ICC=0.80-0.94 and ICC=0.60-0.94) was shown for pain intensity scores. The inter-rater and test-retest reliability for the overall pain intensity score was excellent (ICC=0.92 and ICC=0.94). Arguments for concurrent validity were indicated, as the overall pain intensity of MOBID-2 as observed by primary caregivers was correlated with physicians' clinical examinations and pain variables. Indication of construct validity was provided, as both Part 1 and Part 2 were satisfactorily correlated with the overall pain score. Part 1 was more highly associated with the overall pain score, suggesting that pain behaviour occasioned by standardised movements may represent a more concrete pain concept than the observation of pain from internal organs, the head and skin, monitored over time.

Paper IV indicated that patients with severe dementia have similar intensity, diagnoses and locations of pain to patients in other stages of dementia. Pain intensity measured by MOBID-2 scoring did not differ between diagnostic groups of dementia. Patients with dementia who received opioids were more likely to demonstrate higher pain intensity scores than mentally healthy controls receiving opioids. It was suggested that these patients received less pain relief than they needed. The isolated increase of opioids may be limited by the high prevalence of ICD diagnoses and opioid side effects. The patients' multi-morbidity and lack of communication require a comprehensive approach to pain assessment and treatment in a multidisciplinary perspective.

Conclusions

The MOBID-2 Pain Scale is based on patients' pain behaviour in connection with standardised active, guided movements of different body parts (Part 1), and pain behaviour related to internal organs, the head and skin (Part 2). Research evidence was provided that lent credibility to MOBID-2 as a reliable and valid nurse-administered assessment tool for inferred pain intensity. Using MOBID-2 in a cross-sectional study, it was suggested that patients with severe dementia and mixed dementia are at great risk of suffering from severe pain.

Validity testing of a behavioural assessment tool is difficult, because the pain scores are indirectly observed and inferred by proxies (nurses). Future research should include

extended testing of concurrent validity, comparing the MOBID-2 Pain Scale with other observational pain tools for patients with dementia. Future research should also explore the prevalence of pain in Norwegian NHs, as the findings presented in this thesis were based on data from only one NH. Implemented in a quality improvement programme, the use of the MOBID-2 Pain Scale may be an important contribution to improving pain assessment and treatment in NH patients.

INTRODUCTION

Advanced age is associated with increased prevalence of dementia, often combined with pain. Although elderly persons tend to have more painful diseases, they have been found to report less pain. They receive fewer analgesic drugs than their younger counterparts. With impaired cognition, patients' ability to report pain decreases, leading to the interpretation by health care professionals that elderly persons with dementia have less pain complaints than mentally healthy controls. Thus, when elderly adults in pain also have severe dementia and reduced communicative abilities, they are at high risk of not being properly diagnosed and treated for pain, which is a major challenge in NHs.

In response to the strong need for improvement in pain assessment and pain management in patients with dementia, several pain behavioural scales have been developed and reviewed. Interestingly, these scales do not systematically assess pain from the musculoskeletal system, and other types of pain, such as pain originating in internal organs, the head and skin.

This thesis is about the development, and reliability and validity testing of the Mobilisation-Observation-Behaviour-Intensity-Dementia (MOBID-2) Pain Scale. The MOBID-2 Pain Scale is a two-part nurse-administered pain assessment tool for patients with dementia, assessing pain from the musculoskeletal system, as well as internal organs, the head and skin.

Moreover, this thesis aims to demonstrate the complexity of the psychometric property testing of a behavioural pain scale in patients with dementia, also shown in Figure 1. A valid and reliable pain scale is a prerequisite for improving pain assessment and management. The complexity of this topic is expressed in several factors, such as the nature of pain, different stages and diagnoses of dementia, staff conditions, the proxy rating process and ethical considerations.

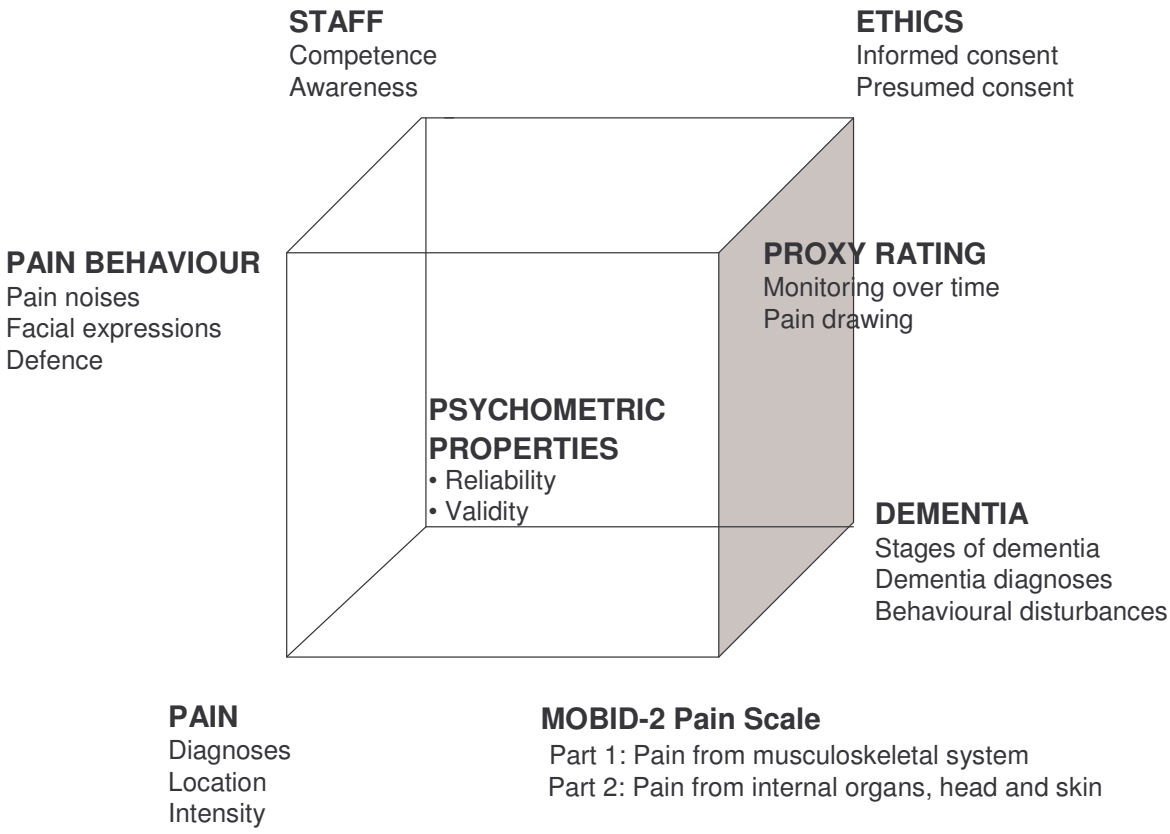

Figure 1. Complexity of the psychometric properties of the behavioural pain scale, the MOBID-2 Pain Scale Part 1 and 2, in patients with dementia as observed by nursing home staff

The importance of relating neuropathology to pain in dementia has been emphasised earlier. Clinical studies on pain include both the "demented elderly" and the "cognitive impaired elderly" patients without more detailed information on the causes of their disorders. Information of the cause of the dementia is important, because it is related to the pathology and to possible changes in the patients' pain. The MOBID-2 Pain Scale was used to explore the relationship between pain intensity and the use of pain medication in NH patients in different stages of dementia and with different dementia diagnoses.

BACKGROUND

DEMENTIA

The prevalence of dementia

The rapid ageing of the population is unique in the history of mankind. This development represents challenges in terms of social justice and security, policy and health care, and the necessity of scientific research. One central challenge in connection with these dramatic demographic changes is the provision of care for the frail elderly with dementia. In prevalence studies of dementia, it is estimated that 24 million people worldwide have dementia today, with 4.6 million new cases of dementia every year, and the number affected is expected to double every 20 years, reaching 81 million by 2040 (Ferri et al., 2005). The rate of increase of Alzheimer's disease and related dementias in developed countries is forecasted to be 100% between 2001 and 2040, but more than 300% in India, China, and Asia. In Norway, the number of people with dementia is approximately 70,000, and in Norwegian NHs more than 80% of the patients are judged to have dementia (Selbaek et al., 2007).

Alzheimer's disease

Dementia refers to a clinical syndrome that has many causes (Friedland and Wilcock, 2000; Mahlen, 2003): a) neurodegenerative diseases (Alzheimer's disease (AD) (50-60%)), Lewy body diseases (DLB) and frontotemporal dementia (FTD) (15-20%))
b) vascular dementia (VaD) (20-30%)
c) secondary dementia, e.g. due to alcohol, tumours.

Dementia is defined as an acquired impairment of intellectual and memory functioning, which not only occurs in association with disturbances at the conscious level. By definition, these patients must have memory disturbances as well as defects in other mental abilities, such as abstract thinking, awareness, personality, judgement, language and neuropsychological disorders, severe enough to cause functional impairment (Engedal and Haugen, 2006; Reisberg, 2006).

The most common cause of dementia in the United States and in Europe is Alzheimer's disease, which is defined by pathological changes in the brain, such as neurofibrillary tangles, neuritic plaques, amyloid infiltration of vessel walls, granulovascular degeneration, and Hirano bodies (Tolnay and Probst, 2002; Hodges et al., 2004; Pantoni et al., 2006). There is

also a loss of neurons and loss of synaptic arborisation. These abnormalities are most severe in the medial basal temporal cortex (hippocampus and amygdale), the basal forebrain, and in the posterior lateral parietal and temporal cortices (den Heijer et al., 2006; Smith et al., 2007; McHugh et al., 2007).

Another common cause of degenerative dementia is Lewy body diseases, manifested as dementia with Lewy bodies and dementia associated with Parkinson's disease. These syndromes are characterised by dementia accompanied by Parkinsonism, visual hallucinations, fluctuating cognition and sleep disturbances (Emre, 2006; McKeith, 2007).

Vascular dementia

Age is an important risk factor for strokes, with prevalence increasing to 1.4% for people aged 75 and above (Khaw, 1996). Infarctions, in which brain tissue is deprived of blood, and haemorrhages are the two major pathological processes. About 85% of acute strokes are due to occlusion of a cerebral artery by primary thromboses or occlusion of the vessel by an embolus (Bruun Wyller, 2003).

Before Alois Alzheimer provided the histopathological description of Alzheimer's disease in 1902, Otto Binswanger (1894) described Binswanger's disease caused by ischemia to the white matter substance (Friedland and Wilcock, 2000). It was regarded as a rare form of dementia, with slowly progressive intellectual impairment, and recurrent stroke-like events. At about 24% of the patients, a stroke is one of the most common diagnoses in the NH (Becker et al., 2003), causing long-term care challenges such as dementia, spasticity and contractures, epilepsy, depression, incontinence, aphasia, personality changes and pain (Evans, 2000).

VaD or multi-infarct dementia is the second most common cause of dementia in the Western countries (Friedland and Wilcock, 2000). To estimate the exact prevalence of VaD is difficult, as different diagnostic and pathological criteria have been used in different studies, and some investigators believe that VaD may be over-diagnosed, while others believe that it is under-diagnosed (Brust, 1988). However, infarction of the brain increases the risk of dementia nine fold (Tatemichi et al., 1992) by injury to the hippocampus, thalamus, or mesencephalon.

Mixed dementia (Alzheimer's disease & vascular dementia)

VaD has to be differentiated from other causes of dementia. The most difficult differential diagnosis is VaD accompanying AD (ADVaD), because (a) VaD can follow a slow progressive course in almost half of patients, and (b) vascular risk factors and cerebrovascular diseases may accompany AD, and (c) it is difficult to disentangle the relative importance of vascular and degenerative factors, and to determine the exact role of vascular lesions seen in neuro-imaging (Amar and Wilcock, 1996). Although, the diagnosis is often made at the post-mortem examination, VaD is estimated to coexist with AD in about 10% to 15% of patients (Friedland and Wilcock, 2000).

PAIN

The neurobiology and psychology of pain

In the Taxonomy Committee of the International Association for the Study of Pain (IASP), Lindblom et al. (1986) defined pain as: 'an unpleasant, sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage. Pain is always subjective. Each individual learns the application of the word through experiences related to injury in early life. Pain is a sensation in a part or parts of the body, but it is also always unpleasant and therefore an emotional experience. Unpleasant abnormal experiences (dysaesthesiae) may be pain but are not necessarily so because, subjectively, they may not have the usual sensory qualities of pain. Many people report pain in the absence of tissue damage or any likely pathophysiological cause; usually this happens for psychological reasons. There is usually no way to distinguish their experience from that due to tissue damage. If they regard their experience as pain, it should be accepted as pain.'

Pain related to nociceptive activation

The centre of pain processes is the integrated model of pain registration by pain receptors (nociceptor): a sensory stimulus involves receptor activation (transduction), the relaying of information from the periphery to the central nervous system (transmission), and neural activity that leads to pain transmission (modulation) (Dahl and Kehlet, 2006). While a number of disorders may cause pain, two types of conditions are part of somatic pain pathogenesis: nociceptive and neuropathical. Nociceptive pain is associated with tissue damage and a

normal nervous system (e.g. pain associated with osteoarthritis), while neuropathical pain is associated with nervous system dysfunction (e.g. diabetic neuropathy or post herpetic neuralgia). These two types of pain frequently coexist.

Nociception, however, is not synonymous with pain; nociception may be necessary for pain to occur, but it is not sufficient to account for pain as a clinical presentation (Turk and Okifuji, 1999). Nociception is a physiological phenomenon, whereas pain is a perceptual one that involves higher central nervous mechanisms and psychology. The patient's pain perception and experience is individual due to several central pain components involving cognitive, behavioural, affective and hormonal factors. These qualities are related to the sensory-discriminative, motivational-affective, cognitive-evaluative, and autonomic-neuroendocrine features, of the lateral and medial pain system (Melzack, 1999; Almeida et al., 2004).

The lateral pain system represents sensory-discriminative pain modulation. The spinothalamic tract, originating in the dorsal horn, mediates the nociceptive stimuli to the lateral thalamus, and activates the primary and secondary somatosensory cortices, the parietal operculum, and the insula. The recognition of pain localisation, the intensity, duration and nature of nociceptive stimuli and the pain threshold are dependent on the lateral pain system being intact, especially the parietal operculum (Scherder et al., 2003a).

The medial pain system represents the cognitive-evaluative (attention), the motivational-affective (affective reaction), the memory (amygdalae, hippocampus) and the autonomic responses (hormones parasympathetic/sympathetic nervous system activation). Tissue damage or damage to the central or peripheral neural system will not always result in overt pain behaviour or suffering. Pain of short duration may have only a brief impact and no long-term consequences. Chronic pain, on the contrary, may lead to suffering, pain behaviour and substantial physical, psychological and social consequences for the patient, and his or her relatives.

Pain related to viscera

Compared to nociceptive pain, which is more easily localised and characterised as distinct sensations, visceral (vegetative) pain may be diffuse and poorly localised, typically referred to somatic sites, with stronger emotional and autonomic reactions (Bielefeldt and Gebhart, 2006). The viscera are unique in that each organ, through thoracic, abdominal, and pelvic viscera, receives nerves from the autonomous nervous system, either vagal or spinal nerves or

pelvic and spinal nerves (sympathetic or parasympathetic). Visceral afferent fibres are contained in nerves that terminate in the spinal cord, except those in the vagus nerve, which terminate in the brain stem and innervate most internal organs of the thoracic, abdominal, and pelvis viscera. Autonomous afferents are important for chemo-nociception, affective dimensions and unpleasantness.

Pain mediators

A number of chemicals that mediate or facilitate the inflammatory process, including bradykinin, prostaglandin, leukotrien, serotonin, histamine, substance P, thromboxane, platelet-activating factor, adenosine and adenosine tri-phosphate (ATP) are central in the pain process. Cytokines (interleukins), tumour necrosis factor and neurotrophins are also generated during inflammation. Some agents can directly activate nociceptor receptors (e.g. vanilloid, cholinerg, GABA, somatostatin and opioid-receptors), while others act indirectly (McMahon and Jones, 2004; Okuse, 2007).

Acute and chronic pain

Acute pain is provoked by tissue damage and comprises both phasic and tonic pain, which persists for a variable period of time until healing takes place (Sullivan et al., 2002). Qualities of acute pain translation are especially related to the lateral pain system. Pain management is most successful when the underlying cause of acute pain is identified and treated specifically and definitively (AGS Panel, 1998). Inherent to the assessment of pain is the need to evaluate acute pain that may indicate new concurrent illness and to distinguish this from exacerbations of chronic pain (Pickering et al., 2006), which is defined as pain beyond the expected time of healing, or more then three to six months (Merskey and Bogduk, 1994). In a large computer-assisted telephone survey, an overall prevalence of moderate to severe chronic pain was defined as pain ≥5 on a 10-point Numeric Rating Scale (1=no pain, 10=worst pain imaginable) and pain duration ≥6 month (Breivik et al., 2006).

An optimal therapeutic response to pain is dependent on an adequate diagnostic differentiation between acute and chronic pain. Chronic pain is a syndrome with multiple consequences for the patient, all of them potential contributors to the patient's experience of pain, which require assessment and treatment to influence the optimal therapeutic outcome. Furthermore, chronic pain is treatable but not curable; improvement is the realistic goal, not

that the pain will diminish. It is often possible to improve functional ability and to reduce the negative influence of the consequences of pain rather than reducing the severity of experienced pain. NH patients and patients with dementia will usually have several different diagnoses and locations of acute and chronic pain, and the onset and duration of pain are subject to major individual differences. In these patients three central challenges have to be added regarding the differentiation between acute and chronic pain:

1. *Reduced ability to remember*. Due to impaired memory and verbal capacity, these patients have a reduced ability to remember their own previous pain experiences and relate them to the actual pain experience and history. They are more or less unable to contribute important information about the development of pain, pain intensity, location and the duration of acute or chronic pain.
2. *Reduced learning ability.* In the chronic pain concept, a central focus is on the influence over time of pain on the body, mind and behaviour, often resulting in 'learned pain behaviour'. Patients with cognitive failure often lack this learning ability, and the consequences of chronic pain differ from those for patients without cognitive failure.
3. *Difficulties in discriminating between acute and chronic pain.* In patients with dementia, standardised mobilisation of the joints makes chronic pain visible by nociceptor stimulation or provocation of musculoskeletal pain. However, it is a question of interpretation and definition whether pain provoked by mobilisation can be defined as chronic or acute pain, or as 'an acute episode of chronic pain'.

The impact of dementia on the pain system

A review of the neurological effects of AD, VaD, and FTD on the medial and lateral pain system concluded that the patient's pain experience may be influenced by the origin of dementia diseases (Scherder et al., 2005). Atrophy and white-matter lesions are neuropathological features common to the dementia subtypes, and the varying degree to which they occur and affect the different areas of the medial and lateral pain systems determines the pattern of changes in pain processing.

It has been concluded that pain tolerance is significantly higher in patients with AD than in non-demented individuals (Benedetti et al., 1999). It was suggested that brain lesions associated with AD involve the medial pain system, affecting the cognitive-evaluative, the motivational-affective, the memory and the autonomic responses. Patients with severe AD

may not reflect, expect or remember pain experiences, and they may react in a different way compared with mentally healthy controls. It was hypothesised that AD leads to a decreased experience of pain (Scherder et al., 2003a). A reduced placebo-related component in AD may even lead to a potentially reduced effect of analgesic treatment, because patients do not expect pain relief from medication. Thus, an increased need was demonstrated for analgesic drugs to compensate for the loss of the placebo mechanisms (Benedetti et al., 2006).

In contrast to AD, patients with VaD or who have suffered a stroke may experience deafferentiation pain from white-matter lesions. The risk of complex regional pain syndromes or post-stroke pain is increased, including paresis of the shoulder girdle, visual deficits and somatosensory deficits (Baron, 2006).

Diagnosis of pain in dementia by fMRI

Analysis by functional magnetic resonance imaging (fMRI) can be used to demonstrate brain responses to standardised external acute pain stimuli, visualised by local cerebral blood flow changes and variations in deoxyhemoglobin content (Rosen et al., 1998; Peyron et al., 2000). In contrast to acute pain stimulation, patients with chronic pain show decreased resting cerebral blood flow in defined brain areas, which may be reverted by analgesic procedures (Peyron et al., 2000).

Until now, only one study has focused on pain diagnostics in dementia using fMRI (Cole et al., 2006). In contrast to the prevailing hypothesis that AD reduces emotional responses to pain, this study concluded that the activity in the medial and lateral pain pathways is preserved in AD patients. In fact, compared with mentally healthy controls, patients with dementia showed greater amplitude and duration of pain-related activity in sensory, affective and cognitive processing regions, consistent with sustained attention to the noxious stimulus. The results of this study show that pain perception and processing may not be diminished in AD, thereby raising concerns about the current inadequate treatment of pain in this highly dependent and vulnerable patient group (Cole et al., 2006). This is a key question, since, if pain experience is not reduced in AD, the reduced prescription of pain medication (Morrison and Siu, 2000; Frampton, 2003; Nygaard et al., 2003; Nygaard and Jarland, 2005; Hutt et al., 2006) would mean that pain is substantially undertreated in this frail population.

The prevalence of pain in nursing home patients

Advancing age is associated with increased prevalence of pain (Ferrell et al., 1990; AGS Panel, 1998; Teno et al., 2004), often caused by musculoskeletal conditions, previous fractures and neuropathies (Feldt et al., 1998). The prevalence of pain in NHs, much of it undertreated, has been documented as ranging from 45% to 83% (Ferrell et al., 1990; Fries et al., 2001; Engle et al., 2001; Stein, 2001; Horgas and Elliott, 2004). About 94% of elderly people suffering from pain were expected to experience chronic pain (Miro et al., 2007). Persistent pain is associated with a significant limitation of daily activities, poorer self-rated health and increased prevalence of anxiety (Gureje et al., 2001). Poor pain assessment and pain management have been found to affect the overall quality of life (Frondini et al., 2007; Hadjistavropoulos et al., 2007), sleep (Vitiello and Borson, 2001; Rainfray et al., 2003; Hellstrom et al., 2004), nutrition (Black et al., 2006), mood (Reid et al., 2003), depression (Snow et al., 2005a; Snow et al., 2005b), healing (Jacquot et al., 1999), the risk of falls (Gostynski, 1991; Cumming et al., 2000), and, in particular, day-to-day functioning (Leveille et al., 2001; Jones et al., 2004).

Until now, no objective biological markers of pain have been identified. However, the evidence for and intensity of pain is based on the patient's description and self-reporting (Turk and Okifuji, 1999). Patients' reports of pain only seem to increase up to the seventh decade of life, despite the increase in pain-associated diseases in old age (Helme and Gibson, 2001). Many elderly living at home or in a NH experience both dementia and pain. The problem of under-diagnosed and untreated pain would therefore appear to be a challenge due to reduced self-reporting capacity (Ferrell et al., 1990; AGS Panel, 1998; Weiner et al., 1999a; Weiner et al., 1999b; Cohen-Mansfield, 2002; Frampton, 2003; Weiner, 2004). Moreover, patients with severe dementia are often excluded from pain studies, and, in studies that include patients with dementia, the frequency of pain differs substantially in patients with different levels of dementia (Gagliese and Melzack, 1997; Helme and Gibson, 2001).

Pain in the musculoskeletal system

Chronic musculoskeletal pain affects over 100 million people in Europe (Woolf et al., 2004). In older people, chronic pain is often experienced in major joints, the back, legs and feet, and it is reported more often than visceral pain and headaches (Helme and Gibson, 2001). In a cross sectional survey of an older rural community in Italy, about one third of the population

was affected by symptomatic peripheral osteoarthritis in knees, hands, and hips, strongly associated with disabilities (Mannoni et al., 2003). About 71% of the veterans in a primary care clinic in New York described pain with multiple localisations, also in coexistence with psychological and social problems (Crosby et al., 2006). Chronic musculoskeletal pain is by far the most common limiting factor on the activities of the ageing population, with an associated risk of reduced mobility, disability, muscle weakness and related impact on quality of life (Woolf et al., 2004). Other studies have shown that musculoskeletal pain caused by osteoarthritis is associated with decreased balance, week knee strength (Jadelis et al., 2001) and risk of falls (Leveille et al., 2002).

Pain in internal organs, the head and skin

There is increasing evidence that ageing substantially affects the way various illnesses may present, painful processes due to internal pathology in particular. Elderly patients with visceral pain conditions are far more likely than younger adults to present atypically, and often with diminished intensity (Helme and Gibson, 2001). Silent ischemia and painless myocardial infarct caused by arteriosclerosis become more frequent with advancing age, so that clinicians should continuously suspect and focus on these diagnoses (Stern, 2003; Stern, 2005). Peptic ulcers, intestinal obstruction and peritonitis are other visceral conditions, often with reduced or absent abdominal complaints (Helme and Gibson, 2001). About 45% of older persons with appendicitis do not have lower-right quadrant pain as a presenting symptom, compared with 5% of younger adults (Wroblewski and Mikulowski, 1991). Headaches are commonly (70%) reported in elderly people (Gunzelmann et al., 2002), but we are not aware of studies addressing chronic headaches in patients with dementia. Living in a NH, 53% of patients are at risk of developing a pressure ulcer (Horn et al., 2002), and skin diseases found in 95% of the patients were described as one of the most prevalent health problems (Black et al., 2006). Pain in connection with genito-urinary infections is quite often described (Leoni et al., 2004). Catheter-associated urinary tract infection is the most common nosocomial infection, accounting for more than one million cases every year in American hospitals and NHs (Tambyah and Maki, 2000). Interestingly, none of the studies discusses this important issue in relation to NH patients with dementia.

Lack of pain treatment in patients with dementia

Although pain is a frequent complaint in the NH, one quarter of NH patients reporting daily pain receive no analgesic medication (Ferrell et al., 1990; Ferrell, 1991; Sengstaken and King, 1993; AGS Panel, 1998; Weiner and Hanlon, 2001; Ferrell et al., 2002; Won et al., 2003; Feldt, 2004; Gibson, 2006). The prescription and administration of analgesics in the NH, occur at rates lower than recommended (Horgas and Tsai, 1998; Nygaard et al., 2003; Nygaard and Jarland, 2005; Hutt et al., 2006; Cornali et al., 2006; Hwang et al., 2006; Jervis et al., 2007). Demented patients receive fewer analgesic drugs than mentally healthy controls, possibly due to older patients being at increased risk of drug-drug interactions as a result of ageing, concurrent co-morbidities and poly-pharmacy (Lindley et al., 1992). Although opioids remain a mainstay in pain treatment associated with surgical procedures, the use of opioid analgesics in elderly people is considered to be associated with adverse drug events, increased length of stay and hospitalisation costs (Oderda et al., 2007). Significant associations between the use of NSAIDs, central nervous system category medications and falls in elderly patients have been demonstrated (Walker et al., 2005; French et al., 2006).

PAIN ASSESSMENT

Pain assessment scales in non-demented persons

Pain assessment is the central prerequisite for adequate pain treatment (Turk and Okifuji, 1999). How a physician thinks about pain affects the way in which he or she assesses a patient who presents with pain. Because of their inherent subjectivity, pain, suffering and disability are difficult to prove, disprove or quantify. Disease or tissue injury is only one factor that contributes to the experience of pain.

The most exact and trustworthy verification of the assessment of pain is the patient's self-reporting, which depends on the patient's memory, verbal capacity, expectations and emotions. Good correspondence has been found between self-reports, disease characteristics, physicians' or physiotherapists' ratings of functional abilities and objective functional performance (Deyo and Diehl, 1983; Jette, 1987). One way of assessing pain in mentally intact people is to have patients' write diaries about their activities (Maunsell et al., 2000; Chambers et al., 2003). The three most commonly used methods of assessing changes in pain intensity and benefit of treatment interventions are the Verbal Rating Scale (VRS) (Seymour et al., 1985), the Visual Analogue Scale (VAS) (Jensen et al., 1986) and the Numerical Rating

Scale (NRS) (Kremer et al., 1981). The McGill Pain Questionnaire includes a descriptive scale of pain intensity, a human figure to mark locations of pain and adjectives from 20 categories reflecting sensory, affective, and evaluative components (Melzack, 1975; Melzack, 2005). Less common measures include various versions of a picture or face scale, and the Descriptor Differential Scale of Pain Intensity (DDS-I) (Jensen and Karoly, 2001). For such pain assessment tools to be used, it is a requirement that the patient is mentally healthy and oriented with respect to time, place and his or her own person.

Proxy rater

In addition to seeking information directly from a patient, information can be obtained from a number of other (proxy) sources. A proxy is defined as a person or agency of substitute recognised by law to act for, and in the best interests of the patient (Grootendorst et al., 1997; Hughes and Preski, 1997). In the context of assessment, the term proxy is used more widely to refer to an informant who has knowledge of the circumstances or condition of the patient (e.g. a caregiver or spouse). This can be helpful in patients with communication difficulties because a proxy will spend much more time with the patient than the physician, and will have opportunities to observe the patient's behaviour over time. Knowing the patient and his pain history may be a prerequisite for valid pain assessment by a proxy (Morello et al., 2007). However, this knowledge will always be subjective, depending on how long and how well a proxy rater has known or knows the patient and on the proxy's own pain experience and skills in pain assessment. Little is known about the validity and reliability of proxy pain reports for patients with dementia, but agreement between patient and proxy reports regarding pain assessment underlines that nurses' perceptions and observations may be an important source (Fisher et al., 2002; Boyer et al., 2004).

Behavioural pain assessment scales

Self-report pain scales cannot be used when dementia increases in severity (Closs et al., 2004). Although research evidence suggests that elderly people with mild to moderate dementia can provide valid pain reports, it is unclear at what level of impairment the validity of self-reports becomes questionable (Feldt et al., 1998; Hadjistavropoulos and Craig, 2002; Closs et al., 2004). Uncertain results may lead to the interpretation that they have less pain complaints than non-demented elderly (Parmelee, 1996; Proctor and Hirdes, 2001).

In dementia, the assessment of pain depends on the ability of health personnel to register and interpret verbal and non-verbal expressions of pain (Prkachin et al., 1994). Each individual episode of pain is complex. The estimate of pain depends on the relationship between the patients' verbal expressions of pain and pain behaviour and the observer's interpretation. Although it is not considered sufficient to rely solely on pain behaviour indicators, such indicators should be assessed in individuals with dementia. External signs have to be observed and interpreted by an external rater, who extrapolates the meaning of behaviour that might be caused by pain (Snow et al., 2004a). However, little is known about the relationship between pain behaviour and the interpretation of overall pain intensity in dementia.

In response to a strong need to assess pain and improve pain management in patients with cognitive impairment, several staff-administered pain behavioural observation scales have been developed (Hurley et al., 1992; Simons and Malabar, 1995; Baker et al., 1996; Ferrell et al., 2000; Feldt, 2000; Kovach et al., 2001; Lefebvre-Chapiro, 2001; Fisher et al., 2002; Villanueva, 2003; Warden et al., 2003; Fuchs-Lacelle and Hadjistavropoulos, 2004; Abbey, 2004; Davies et al., 2004; Snow et al., 2004b; Defrin et al., 2006; Stevenson et al., 2006; Lautenbacher et al., 2007; Morello et al., 2007). Most of these scales have been reviewed, some with promising results (Herr et al., 1998; Stolee et al., 2005; Zwakhalen et al., 2006a).

Since 1992, more than 20 pain assessment instruments have been developed to register acute and chronic pain indirectly in older persons with dementia (Table 1). These instruments are based on observations by a rater who assesses the patients' behaviour and functioning, including facial and or body language, and other aspects such as sleep, appetite, daily activities and social indicators. However, the interpretation of pain behaviour is challenging. There is strong evidence that pain behaviour indicators such as guarding, bracing or grimacing are relevant (Hadjistavropoulos et al., 2000a; Keefe et al., 2001), but these indicators may be absent or difficult to interpret, because symptoms attributed to dementia may also be indications of pain (Herr, 2002). Furthermore, behavioural indicators are more likely to be associated with acute pain, which is less prevalent than persistent pain in older adults (Gibson, 2006). Distinguishing pain behaviour from psychological distress such as fear, depression, or restlessness caused by dementia is a prerequisite for valid pain assessment.

Short observational scales

Clinically relevant measures can be categorised into those that are short (comprising 10 items or less) and those that are extended (comprising more than 10 items). Table 1 includes 10 short measures of 10 or less items such as the Discomfort Scale (DS-DAT) (Hurley et al., 1992), Checklist of Nonverbal Pain Indicators (CNPI) (Feldt, 2000), Assessment of Discomfort in Dementia (ADD) (Kovach et al., 2001), Doloplus-2 (Lefebvre-Chapiro, 2001), the pain report of the Mini Data Set (MDS) (Fisher et al., 2002), Pain Assessment in Advanced Dementia (PAINAD) (Warden et al., 2003), the Proxy Pain Questionnaire (PPQ) (Fischer et al., 2003), Abbey Scale (Abbey, 2004), modification of the Facial Action Codin System (FACS) (Lautenbacher et al., 2007) and the measurement of pain in non-verbally communicating patients (ECPA) (Morello et al., 2007). These scales differ with respect to the use of proxy raters such as a collaborative informant, who is familiar with the patient, or an observer, who is unfamiliar with the patient. When a proxy rater knows the patient, he may be better able to judge changes in behaviour, appetite, restlessness, isolation or sleep. Knowledge of the patient is required by the DOLOPLUS-2, Abbey Scale and ECPA. A rater who does not need to know the patient can complete the remaining scales.

Extended observational scales

Lengthy scales (between 15 and 60 items) include more behaviour indicators or psychosocial observations are also shown in Table 1, through the Observational Behavior Tool (Simons and Malabar, 1995b), the Behavioral Checklist (Baker et al., 1996), Geriatric Pain Measure (GPM) (Ferrell et al., 2000), Pain Assessment in Dementing Elderly Scale (PADE) (Villanueva, 2003), Non-communicative Patients Pain Assessment Instrument (NOPPAIN) (Snow et al., 2004b), Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) (Fuchs-Lacelle and Hadjistavropoulos, 2004), the Pain Assessment Tool for Use with Cognitive Impaired Adults (Davies et al., 2004), the Discomfort Behavior Scale (DBS) (Stevenson et al., 2006) and the Non-Communicative Pain Checklist (NCCPC-R) (Defrin et al., 2006). Extended scales support the potential of the tool, because they may be likely to encompass the varied responses of patients who suffer very diverse effects of brain pathology (Hadjistavropoulos et al., 2007). Some items of the PACSLAC require an informant, while in the case of the other scales, the rater may be unfamiliar with the patient.

Psychometric property testing of behavioural pain scales for patients with dementia has not been completed for all measures. Internal consistency is reported for the Abbey Scale (0.74-0.81), CNPI (0.54-0.64), DS-DAT (0.86-0.89), DOLOPLUS-2 (0.82), PAINAD (0.50-0.67), PADE (0.24-0.88), and PACSLAC (0.85). Unsatisfactory and unreported internal consistency increases the risk that not all items assess the same construct, i.e. pain. In a process of item reduction and translation of the PASCLAC into Dutch, the PACSLAC-D retained 24 of 60 items, including the observations that the patient may be irritable, upset, restless or sad looking (Zwakhalen et al., 2007). These behaviours are also typical of and frequent in psychiatric disturbances related to dementia, as the prevalence of behavioural disturbances ranges between 60% and 80% in NHs (Cipher et al., 2006).

It is easier to achieve good internal consistency in scales with more than 10 items (Pallant, 2005). Very short scales like the MDS, PPQ, and PAINAD may, therefore, produce questionable information. Moreover, the PAINAD includes respiratory items, which, while of importance, may not be typical of pain expression. Other short scales like the DOLOPLUS-2, DS-DAT, and Abbey demonstrated satisfactory results. However, the DS-DAT provided validity information involving fever as a gold standard illness, which is not comparable with pain. The observation of pain behaviour during everyday activities or body movements is performed using DOLOPLUS-2, NOPPAIN, PACSLAC and ECPA. These movements are spontaneous, and not standardised and guided.

Pain components

As demonstrated in Table 2, pain scales include different components of the pain process. The motivational-affective pain component (A) expressed by pain behaviour such as facial expression, pain noises and/or defence is included in most of the scales. The sensory-discriminative pain component (S), such as pain location, pain intensity and pain duration, is presented in scales like the GPM and ADD. None of the tools registers all these three components. One instrument includes a question about pain duration (acute or chronic pain) (Abbey, 2004). While of importance, memory disturbances and different pain localisations with different onsets of pain make the registration of pain duration challenging. Furthermore, it is difficult to differentiate between acute and chronic pain behaviour, although such knowledge has serious consequences for pain treatment.

Table 1. Characteristics of clinically relevant observational pain behaviour scales for persons with dementia

Instrument	Number of items	Pain components				Pain characteristics					Pain scores		
						Location		Intensity	Duration		Range	Sum	Overall
		S	A	C	Au	MS	IO		Acute	Chronic			
DS-DAT (Hurley et al., 1992)	9		x					x				x	
Observational Behavior Tool (Simons and Malabar, 1995)	25		x		x								
Behavioral checklist (Baker et al., 1996)	20		x										
GPM (Ferrell et al., 2000)		x								x		x	
CNPI (Feldt, 2000)	6		x			x			x			x	
ADD (Kovach et al., 2001)	10	x			x		x						
Doloplus-2 (Lefebvre-Chapiro, 2001)	10		x			x					0-30	x	
MDS (Fisher et al., 2002)	3			x				x				x	
PADE (Villanueva, 2003)	24		x			x		x					
PAINAD (Warden et al., 2003)	5		x								0-10	x	
PPQ (Fischer et al., 2003)	3							x			0-10		x
Abbey Scale (Abbey, 2004)	6		x		x		x		x	x	0-18	x	
NOPPAIN (Snow et al., 2004b)	15		x	x		x		x					x
PACSLAC (Fuchs-Lacelle and Hadjistavropoulos, 2004)	60		x		x	x					0-60	x	

Pain Assessment for Use in Cognitive Impaired People (Davies et al., 2004)	16	x	x	x						
DBS (Stevenson et al., 2006)	17	x								x
NCCPC-R (Defrin et al., 2006)	27	x	x				x		0-81	x
FACS (Lautenbacher et al., 2007)	10	x			x	x				
ECPA (Morello et al., 2007)	8	x		x				x	0-32	x

S: sensory-discriminative, A: motivational-affective, C: cognitive-evaluative, Au: autonomic-neuroendocrine; MS: pain from the musculoskeletal system; IO: pain from internal organs, the head and skin; DS-DAT: Discomfort Scale, GPM: Geriatric Pain Measure, CNPI: Checklist of Nonverbal Pain Indicators, ADD: Assessment of Discomfort in Dementia, MDS: pain report of the Mini Data Set, PADE: Pain Assessment in Dementing Elderly Scale, PAINAD: Pain Assessment in Advanced Dementia, PPQ: Proxy Pain Questionnaire, NOPPAIN: Non-communicative Patient's Pain Assessment Instrument, PACSLAC: Pain Assessment Checklist for Seniors with Limited Ability to Communicate, DBS: Discomfort Behavior Scale, NCCPC-R: Non-Communicative Pain Checklist, FACS: modification of the Facial Action Codin System, ECPA: measurement of pain in non-verbally communicating patients.

The cognitive-evaluative (C) pain component is included in the MDS and NOPPAIN, which ask the patient about his pain ('Do you have pain?'). In severe dementia, this item may be questionable, possibly leading to misinterpretation by staff if the patient does not understand the question. Autonomic-neuroendocrine (Au) pain reactions are included in the Observational Behavior Tool, ADD, Abbey, Pain Assessment Tool for Use with Cognitive Impaired Adults, PASCLAC, and NCCPC-R. These items may be questionable in elderly patients with chronic pain. Autonomic measures seem to be of little relevance in pain syndromes of a musculoskeletal nature (Flor, 2001), while they play a major role in vascular pain problems (migraine headaches, Reynaud's disease), in pain syndromes related to sympathetic dysfunction (complex regional pain syndromes) and in laboratory investigations that include acute pain stimuli. Measurements of the heart rate, skin temperature or blood pressure will be influenced by changes in the skin, multi-morbidity of the patients and drug consumption.

Table 2. Different components of the pain process

Pain components		**Examples of items**
Motivational-affective	(A)	• Pain noises: 'Ow, that hurts', moaning, groaning, mumbling • Facial expression: tighten face, change in eyes, frowning, creasing forehead, grimacing • Defensive behaviour: Body language such as pulling away, freezing, stiffening
Sensory-discriminative	(S)	Pain location, intensity, duration
Cognitive-evaluative	(C)	Memory, reflection, expectation
Autonomic-neuroendocrine	(Au)	Blood pressure, pulse, sweat, red face

Pain intensity scores

Scoring procedures for an assessment tool may not be straightforward. To get an overall impression of pain intensity, mean or sum scores for pain behaviour are usually calculated. The addition of these observations may not necessarily be equivalent to pain intensity, as several behaviours are typical for pain as well as dementia. It is a prerequisite that the items used represent the same phenomenon, pain. If pain behaviour signalises pain, one key

question is how pain behaviour can be inferred to a valid and reliable pain intensity score. The pain assessment tool should also be useful for, for example, patients with Parkinson's disease, contractures, paresis and aphasia, whose ability to express pain behaviour will be substantially reduced. The interpretation of observed pain behaviour in patients who are no longer able to express such behaviour has to be guarantied by an overall pain intensity scoring system and not by sum scoring of individual pain behaviours. This is required by NOPPAIN, in which the rater has to estimate the overall pain at the end of the measure. The other pain scales use a sum score system for pain behaviour.

Why a new pain assessment scale?

Researchers tend to dismiss existing scales and develop new instruments, which is easier than establishing good reliability and validity for already existing ones (Streiner and Norman, 2006). Reviews of pain assessment tools for patients with dementia conclude that there are promising instruments in development. These studies also underline that there is insufficient evidence of reliability and validity testing, and they do not recommend any one tool for use in all populations and settings at present (Herr et al., 2006; Hadjistavropoulos et al., 2007). When starting our project, we were not convinced of the necessity of developing a new instrument, as approximately 20 scales had already been developed in this context. Instead, our aim was to translate NOPPAIN (Snow et al., 2004b) into Norwegian and to test the tool with respect to psychometric properties. However, the lack of registration of pain in internal organs, the head and skin, and inconsistency in the scoring system were considered to be unsatisfactory.

A new pain assessment tool was developed to address shortcomings in existing scales and to take at least three substantial new aspects into consideration:

1. Movement-related pain behaviour seems to be of clinical significance (Mercadante and Arcuri, 2006), but few attempts have been made to investigate the utility of using a standardised movement protocol (Gibson, 2006). A shortcoming of existing scales is that pain behaviour in connection with movements is only observed in everyday activities as they occur naturally (Feldt, 2000; Lefebvre-Chapiro, 2001; Villanueva, 2003; Snow et al., 2004b; Fuchs-Lacelle and Hadjistavropoulos, 2004; Davies et al., 2004). However, pain tends to change the way activities are performed (Magnussen et al., 2004). Changes may be subtle and not easily observed during everyday activities, as people may simply move less, or

change the way they move in order to avoid pain (Lethem et al., 1983; Vlaeyen and Linton, 2000; Hasenbring et al., 2001). To better reveal pain behaviour related to the musculoskeletal system, a protocol of standardised active, guided movements of all body parts was included in the MOBID and the MOBID-2 Pain Scale.

2. Pain from internal organs, the head and skin gives rise to frequent complaints in elderly persons, but may be difficult to diagnose because it is often widespread, diffuse and poorly described (Giamberardino, 2005). In dementia, the assessment of such painful conditions may be even more challenging, and prevalence data are incomplete. So far, none of the existing pain tools systematically registers behaviour that might be related to pain from internal organs, the head and skin. We considered primary caregivers to be key persons in the observation of such behaviour, as they are familiar with the patient and his usual behaviour. The design of the two-parted MOBID-2 Pain Scale is in line with Hadjistavropoulos et al. (2007), who argued that pain from the musculoskeletal system often coexists with other co-morbid conditions, implying that disease-modifying therapies are needed to diminish pain.

3. In the MOBID and MOBID-2 Pain Scale, primary caregivers are encouraged to interpret each test item and the overall pain independently and to judge whether their observations are related to pain or to behavioural disturbances due to dementia. Usually, observational pain tools estimate total pain intensity by summing scores for separate pain behaviours. Such scoring procedures may be uncertain, as patients with dementia may not present pain behaviour at all, or use less obvious indicators such as agitation or aggression. This is one of the key problems, since the prevalence of behavioural disturbances is high in dementia (Cipher 2006).

AIMS OF THE STUDY

The overall aims of this study were:

Paper I. To describe the development of the nurse-administered Mobilization-Observation-Behaviour-Intensity-Dementia (MOBID) Pain Scale for older persons with dementia. To investigate the reliability and validity of the scale, including the key question of whether the presence of pain, pain behaviour indicators and pain intensity in patients with dementia can be assessed by MOBID.

Paper II. To examine the extended intra-rater and inter-rater reliability of the MOBID Pain Scale by external raters, using video recordings. In particular, we wanted to focus on the reliability of pain behaviour indicators and pain intensity scores for individual items, and the overall pain scores.

Paper III. To develop and test the extended instrument, the Mobilization-Observation-Behaviour-Intensity-Dementia (MOBID-2) Pain Scale, in order to also assess behaviour that might be caused by pain from internal organs, the head and skin. In particular, we wanted to focus on the validity of MOBID-2, comparing test scores with the physicians' pain examination of the patient and other types of pain indicators.

Paper IV. To explore pain among NH patients with different levels of dementia and dementia type (AD, VaD, and ADVaD), and to explore the relationship between the MOBID-2 pain intensity scores and the use of pain medication assessed in the clinical setting of a cross-sectional study.

METHODS AND PARTICIPANTS

INSTRUMENT DEVELOPMENT

Focus group interview

The MOBID and the MOBID-2 Pain Scales were developed by focus group interview, including an expert panel experienced in the treatment and care of elderly persons with dementia, and/or experienced in the examination of psychometric properties of pain assessment tools: one registered nurse (RN), one licensed practical nurse (LPN), two physicians, and two physiotherapists. A focus group interview is a discussion among a small group of informants (six to twelve people), in which they talk freely and spontaneously about themes considered important to the investigation under the guidance of a facilitator (Streiner and Norman, 2006). Normally, the persons of interest would be included in this interview, but this was not possible with demented patients.

Devising the items

In Paper I, the MOBID Pain Scale was developed to capture pain related to the musculoskeletal system during standardised active, guided movements in patients with dementia. A process of item generation and subsequent reduction was applied, and reliability and validity were tested in a clinical setting and also using video recordings. Five active movement items were retained. The tester was to guide the patient to (1) open both hands, (2) stretch both arms towards the head, (3) stretch and bend ankles, knees and hips, (4) turn over in bed to both sides and (5) sit at the bedside. One observation item consisting of the patient lying in bed, and one item consisting of brushing teeth/mouth care were removed from the scale because of lower Cronbach's alpha coefficient.

Based on our own clinical experience and a survey of the literature (Hurley et al., 1992; Ekman, 1993; Simons and Malabar, 1995; AGS Panel, 1998; Hadjistavropoulos et al., 2000b; Craig et al., 2001; Villanueva, 2003; Warden et al., 2003; Fuchs-Lacelle and Hadjistavropoulos, 2004; Abbey, 2004; Snow et al., 2004b; Defrin et al., 2006; Herr et al., 2006), three key indicators of pain behaviour were selected, accompanied by explanatory words: 'Pain noises' ('That hurts!', groaning, moaning, gasping, screaming), 'Facial expression' (grimacing, frowning, tightening mouth and closing eyes), 'Defence' (freezing, guarding, pushing and crouching). These aspects of pain behaviour have usually been

included in staff-administered instruments (Stolee et al., 2005). In MOBID, nurses were encouraged to pay attention to the patient's pain behaviour, observe the patient before starting mobilisation, clearly explain what was going to happen, mobilise the patient gently through the activities and reverse the movement immediately if pain behaviour was perceived. Observations were rated after each activity by ticking the boxes for 'Pain noises', 'Facial expression' and 'Defence', and inferring the observation into pain intensity by putting a cross on the line for the 0-10 point Numerical Rating Scale (NRS) (Jensen et al., 1999), answering the question: 'How intense do you regard the pain to be?'

In the extended MOBID-2 Pain Scale, discussed in **Paper III**, MOBID is renamed as MOBID-2 Part 1. In MOBID-2 Part 2, the nurse was encouraged to assess behaviour presenting other types of pain that might originate from the (6) head, mouth and neck, (7) heart, lung and chest wall, (8) the abdomen, (9) the pelvis and/or genital organs and (10) the skin. Pain behaviour was to be monitored retrospectively over time (today, or during the last few days up to one week), and it could be caused by a disease, wound, infection and/or injury. To increase the nurse's awareness, a pain drawing (front and back) of a human body was included in order to register the possible pain locations. The caregiver was encouraged to put one or more crosses on this pain drawing, indicating the observed pain behaviour (Pain noises, Facial expression and Defence), and to infer pain intensity by putting a cross on the line for the 0-10 point Numerical Rating Scale (NRS). Finally, after scoring the 10 separate items, an independent overall pain intensity score was reported, again using the NRS.

If overall pain was judged to be above three on the NRS (Jensen and Karoly, 2001), the test result was to be reported to the physician responsible for the patient, with a view to providing appropriate treatment and care.

Nursing home patients

The Bergen Red Cross NH is one of the largest NHs in Norway, including units for long-term care, rehabilitation, specialised dementia care and palliative care. Inclusion criteria for the study were: age>65 years, and a regular family visitor or legal guardian; exclusion criteria were delirium, psychosis, and/or short stay admission (≤4 weeks). In **Papers I and II**, 26 patients with severe dementia and chronic pain (>3 months) (Merskey H, 1986; Merskey H et al., 1994) were included. In **Paper III**, 77 patients with severe dementia with

or without pain met the criteria for participation. In **Paper IV**, 181 consecutive, long-stay NH patients at different stages of dementia and with different dementia diagnoses were included.

Nursing home staff

Two separate groups of the MOBID Pain Scale raters participated in **Papers I** and **II**. The first group consisted of the patients' primary caregivers (N=11), who were familiar with the patients' habits and regular behaviour. The second group consisted of external raters A, B, and C (N=3), who did not know the patients. In **Paper III**, each patient was assessed by a set of two nurses (N1 and N2), who were familiar with the patients' habits and had had responsibility for the patient during the last four weeks. Altogether, 14 sets of nurses (N=28) participated in the testing of the 77 patients. In **Paper IV**, primary caregivers (N=43), who were familiar with the patients' habits tested the patients using MOBID-2. Before data collection, the raters received a standardised briefing in which they were given basic information about dementia, pain physiology, pain behaviour and pain assessment. They practised the use of the MOBID or MOBID-2 Pain Scale in at least three patients. In **Papers I** and **III**, two physicians from the NH participated, and four physicians in **Paper IV**.

Examination

In **Papers I-IV**, demographic information about the participants was taken from the patients' medical charts. Together with the primary caregivers, a geriatric study nurse rated each patient's cognitive function using the MMSE (Folstein et al., 1975), severity of dementia using the Clinical Dementia Rating (CDR) (Hughes et al., 1982) and Severe Impairment Rating Scale (SIRS) (Rabins and Steele, 1996). Measurements of psychiatric and behavioural changes included the Cornell Scale for Depression in Dementia (Alexopoulos et al., 1988), Neuropsychiatric Inventory (NPI) (Cummings et al., 1994), as well as the Activities of Daily Living scale (ADL) (Mahoney and Barthel, 1965, Sheikh et al., 1979, Laake et al., 1995). The physicians responsible for diagnostics and treatment collected the data about medical conditions (ICD-10), dementia type and pain variables. This included information about pain diagnoses, pain locations, pain treatment (World Health Organisation, 1996) and pain intensity obtained using the NRS (Jensen and Karoly, 2001). In **Paper IV,** dementia was also diagnosed according to the international classification of diseases (ICD-10) (World Health Organisation, 1993), Diagnostic and Statistical Manual of

Mental Disorders (American Psychiatric Association, 1994) based on history, physical and mental examination, routine laboratory tests and cerebral Computer Tomography (cCT) of the head (71% of the patients).

Video recordings

When the patients were guided through the MOBID procedure in **Paper I**, the patients' behaviour during the standardised movements was recorded by continuous video recording (MOBID-v) using a stationary camera (at a distance of 3.80 metres) and a mobile camera. Voices and noises made by patient and staff were documented using a sensitive microphone. The operator processed the video recordings (N=26) using a visual dictionary (Ekman and Friesen, 1969) for film frame, motion time and noises. In the final presentation, each MOBID item was announced by a short title. The film sequence for each patient lasted six to eight minutes, resulting in three hours of film material, which formed part of the database in **Papers I** and **II**.

Test procedures

In **Paper I**, the patients' primary caregivers observed two to three patients each during regular morning care and rated overall pain intensity using an NRS after care. Shortly afterwards, the patients were assessed by their caregivers using the MOBID procedure at the bedside (MOBID-b), which was also recorded in video recordings (MOBID-v). About four to six days after the bedside assessment, each primary caregiver assessed her own video recording and repeated the scoring (MOBID-v). In addition, three external raters (A, B and C) assessed the 26 videos concurrently and independently. Face validity was examined by an expert panel.

In **Paper II**, the intra and inter-rater reliability of the MOBID Pain Scale was reported by the raters A, B, and C on day 1, 4 and 8. They watched the videos and filled in the MOBID form for observed pain behaviour for each item, inferred pain intensity and overall pain intensity.

In **Paper III**, the inter-rater reliability of the MOBID-2 Pain Scale was assessed by two groups of nurses who rated the patients concurrently and independently in a clinical setting. Retesting was performed the next day. The time needed to fill in MOBID-2 was recorded.

Two physicians collected information regarding pain variables on the same day. Face validity was examined by an expert panel.

In **Paper IV**, 181 patients were assessed by their primary caregivers, who used the MOBID-2 Pain Scale in a clinical setting. The time needed to fill in the MOBID-2 was recorded. Four physicians collected information regarding pain variables on the same day.

STATISTICAL ANALYSES

Reliability

Reliability is a prerequisite for validity (Rothstein and Echternach, 1993), and no measure should be used without evidence of both reliability and validity (Jensen et al., 1999). Reliability is the degree to which test scores are free from errors of measurement. Internal consistency, intra-rater, test-retest and inter-rater reliability are attributes of reliability used in this thesis.

Internal consistency expressed by Cronbach's alpha (α), the corrected item-total correlation and the term 'α if item deleted' were calculated for each item in MOBID and MOBID-2 in **Papers I** and **III**. Internal consistency refers to the degree to which the items that make up the scale measure the same underlying construct, and care should be taken not to include items that assess a different construct (Streiner and Norman, 2006). There is no standard for what constitutes an acceptable coefficient of internal consistency. An α in the vicinity of 0.70 has been suggested as being sufficiently high (Polit and Beck, 2006). Cronbach's α formula is the most commonly used indicator of internal consistency, but it is quite sensitive to the number of items in the scale. For short scales (<10 items), it may be appropriate to report the corrected item-total correlation, which gives an indication of the degree to which each item correlates with the sum of all other items. The step 'α if item deleted' indicates the impact of removing the item from the scale. These values are compared with the final α value obtained (Pallant, 2005). If any of the values are higher than the final α value, it should be discussed whether to remove the item from the scale.

Intra-rater reliability is the consistency with which one rater assigns scores to a single set of responses on two occasions. If a rater uses video recording, as was the case in **Papers I** and **II**, she can observe the same pain behaviour on different dates. Because the behaviour being assessed is identical on both occasions, any variability in scores is, in fact, related to measurement errors on the part of the rater. If the function to be tested is performed repeatedly, as in the test-retest procedure used in **Paper III**, errors from the instrument, from the application of the instrument and also changes in the behaviour of the subject being tested may cause variability. It may be unreasonable to believe that individual measurements of chronic pain can be easily reproduced, because pain is a changing phenomenon (Domholdt, 2005). The test-retest reliability of a pain assessment scale is affected by intra-subject variability, which should not be regarded as a measurement error. As performed in **Paper III**, test procedures should be chosen in which raters act consistently, in order to

detect any clinical changes in the patients. Thus, test-retest reliability is also an important step in the validation process of a new method.

Inter-rater reliability is the consistency of scores between different raters **(Paper I-III)**. This is determined when two or more raters judge the performance of one group of subjects at the same point in time (Domholdt, 2005). The reliability of observations can be estimated in different ways. When comparing paired assessments, one is concerned with the relationship between the two measures (relative reliability) and the magnitude of the differences between the two assessments (absolute reliability). The intra-class correlation coefficient (ICC) denotes relative reliability and measures the intra-rater and inter-rater reliability of subjective assessments (Ottenbacher and Tomchek, 1993). In this thesis, intra and inter-rater and test retest reliability for pain intensity were analysed by intra-class correlation coefficient (ICC) model 1,1 (Shrout and Fleiss, 1979), which is equivalent to the SPSS-model 'one-way random'.

In order to assess absolute reliability and the differences between the two measurements, the within-subject standard deviation (s_w) was also calculated, which includes both random and systematic components of measurement error and is expressed in the same metric unit as the measurement tool (Bland and Altman, 1996).

Additionally, in **Papers I-III**, the intra-rater, inter-rater and test-retest reliability of observed pain behaviour indicators in MOBID, MOBID-2 Part 1 were analysed by kappa (κ) statistics, as were pain localisation on the pain drawing in MOBID-2 Part 2 . This test provides a measure of the concordance between the raters and is chance-corrected. The interpretation of κ was: ≤0.20 (poor), 0.21-0.40 (fair), 0.41-0.60 (moderate), 0.61-0.80 (good), ≥0.81 (very good agreement) (Altman, 1995).

Validity

Measurement validity is the appropriateness, meaningfulness and usefulness of the specific inferences made on the basis of the test scores (Domholdt, 2005). There is no simple, absolute, direct test of validity; instead, evidence is brought to bear from a variety of sources. Research evidence can add to the argument for validity, but it can never directly or absolutely test the correctness of a construct (Rothstein and Echternach, 1993). For attributes such as pain, no gold standard or clear-cut indicator exists, making the validation process for a pain assessment scale challenging. The validation of a scale involves the collection of

empirical evidence concerning its use. A pain assessment scale for patients with dementia will be valid if it adequately measures the pain characteristic in question (e. g. intensity, location, duration of pain) and not behavioural disturbances relating to dementia (e. g. depression, restlessness, anxiety). Moreover, a scale will be valid if it reflects changes in pain experiences, such as after pain treatment, also expressed by the responsiveness of a scale. In this thesis, arguments for the face-, construct- and concurrent validity of the MOBID and the MOBID-2 Pain Scale were examined.

Face validity: One issue that must be decided before the items that make up a scale are selected is whether or not they have face validity (Streiner and Norman, 2006), i.e. do the items actually measure what they superficially appear to measure? If the item appears irrelevant, then the respondent may omit it, irrespective of its possible excellent psychometric properties. To explore face validity, the MOBID (**Paper I**) was presented to a focus group consisting of two RNs, two LPNs, two physiotherapists, an occupational therapist and two physicians, all experienced in the evaluation and management of pain in NH patients. The group considered the MOBID test procedure to be a feasible means for nurses to identify pain behaviour related to musculoskeletal pain in connection with morning care. However, they suggested adding items to capture pain not necessarily provoked by movement, such as visceral- and neuropathic pain and headache syndromes.

This was taken into account in the extended MOBID-2 Pain Scale, which included five items concerning pain from internal organs, the head and skin. As commented by the focus group, the judgement of a demented patient's pain experience will always be challenging, especially when pain stems from the head, internal organs or skin. It should therefore be a prerequisite that the rater is familiar with the patient's usual behaviour and that pain behaviour is monitored over time.

Construct validity: Construct validity involves testing a scale, not against a single criterion, but in terms of theoretically derived hypotheses concerning the nature of the underlying variable or construct (Pallant, 2005). As patients with dementia and pain tended to avoid painful movements and thereby concealed acute and chronic pain, MOBID included standardised guided movements to reveal pain in the musculoskeletal system. To explore the construct validity of the MOBID Pain Scale in **Paper I,** the following theoretical questions were examined using the non-parametric Wilcoxon Signed Rank Test (Pallant J, 2005): 1) Is overall pain intensity less captured during regular care activities than during standardised, guided movements using MOBID Pain Scale? 2) Are pain intensity scores for MOBID items

obtained in a bedside situation different from those obtained from watching the videos? 3) Is the ability to observe pain behaviour using the MOBID Pain Scale dependent on knowing the patient? Finally, Spearman Rank Order Correlation was used to examine the association between the maximum and mean pain intensity scores for each test item and overall pain intensity. The question of whether the number (0-3) of observed pain behaviour indicators is related to the staff's interpretation of pain intensity was calculated by one-way between groups ANOVA with linear trend, comparing one independent variable (pain behaviour) with one dependent continuous variable (pain intensity) (Domholdt, 2005; Pallant, 2005). In **Paper III**, construct validity was examined with respect to the association between the overall pain intensity score and the maximum item score for MOBID-2 Part 1 and Part 2, calculated using Spearman's Rank Order Correlation (rho).

Concurrent validity: Concurrent validity is an issue when a new tool is compared with a measurement standard (Domholdt, 2005). The association between the overall pain intensity in MOBID-2 as assessed by nurses and other parameters of pain derived from physicians' clinical examinations, was calculated using Spearman's Rank Order Correlation with respect to the 1) number of pain diagnoses, 2) number of pain locations, 3) number of pain medications according to World Health Organisation's analgesic ladder (WHO I-III), and 4) pain intensity scores assessed using NRS.

In **Paper IV**, one-way ANOVA was used for comparisons between the groups for continuous variables. Pair wise between-groups comparisons were provided by post hoc tests (Bonferroni correction) (Field, 2006). Two-way ANOVA was used to compare pain intensity scores for the MOBID-2 Pain Scale as the dependent variable with levels of dementia, dementia diagnoses and pain medications (independent variables). For the ordered categories (levels of dementia and pain medication categories), linear contrast was used to examine trend in relation to level. Simple contrast was used to compare different types of dementia diagnoses, using no diagnosis as the reference category.

The data were analysed using SPSS for Windows 13.0.

APPROVAL PROCESS

In this thesis, the protocol and the consent procedure for the thesis, including video recording, were approved by the Regional Committee for Medical Research Ethics (REK-Vest) and the Norwegian Data Inspectorate. The approval of the Norwegian Directorate for Health and Social Affairs (www.shdir.no) was a prerequisite for data collection, including staff being released from their duty of confidentiality. The fact that patients with dementia cannot give informed consent and that they lack an understanding of the consequences of the research project were arguments used by the Directorate to reject approval. Furthermore, they argued, presumed consent by relatives is not possible, because it is not stated whether they are aware of patient's interests. Finally, they argued that patients with dementia are vulnerable and have to be protected in connection with research, and the use of video recording in particular.

In order to take account of legal and ethical considerations, our application was improved with the help of a qualified lawyer, experts in ethics and colleagues, and a revised application was sent to the Norwegian Ministry of Health and Care Services. The scientific protocol was finally accepted on the basis of the argument that it would be unfavourable to preclude research into dementia on the basis of the lack of an informed consent cause. The Norwegian Government supports increased research into geriatrics and patients with dementia, because research can enrich the lives of the participants and increase awareness, competence and involvement by staff, and it may also improve pain assessment and treatment. It is a prerequisite, however, that relatives are able to give presumed consent, which refers to an attitude or belief based on reasonable evidence or grounds that have been already proven, but that has no value as explicit evidence. It refers to an idea that is taken to be true, although it is not known for certain (Tottoczko, 2003).

In this thesis, verbal and written informed consent was obtained in direct conversation with the patient and his or her legal guardian, usually a family member or advocate; collateral source consent was required for all patients, given their level of cognitive impairment. The study was approved by REK-Vest (no. 190.04), and the Data Inspectorate (no. 11529).

REVIEW OF PAPERS

I Mobilization-Observation-Behaviour-Intensity-Dementia Pain Scale (MOBID): Development and Validation of a Nurse-Administered Pain Assessment Tool for Use in Dementia

Husebo BS, Strand LI, Moe-Nilssen R, Husebo SB, Snow AL, Ljunggren AE

Journal of Pain and Symptom Management 2007:34:67-80.

Background: Pain assessment in older persons with severe dementia is a challenge due to reduced self-reporting capacity, and lack of movement-related behavioural pain assessment instruments.

Objectives: To describe the development of the Mobilization-Observation-Behavior-Intensity-Dementia Pain Scale (MOBID) and to investigate its reliability and validity.

Methods: Nursing home patients (n=26) with severe dementia were included. Their primary caregivers assessed the patients' pain intensity during regular morning care and using MOBID, at the bedside and on the basis of video recordings. External raters completed MOBID by rating the videos.

Results: The internal consistency of MOBID indicated high Cronbach's alpha (α=0.90) after deleting the items 'at rest' and of 'teeth/mouth care'. MOBID revealed significantly more pain than did pain scorings during regular morning care, and video observation demonstrated higher pain intensity than bedside scoring. The inter-rater and intra-rater reliability for inferred pain intensity was high to excellent (ICC=0.70-0.96), but varied between poor to excellent for pain behaviour indicators (κ=0.05-0.84).

Conclusion: The registration of pain behaviour during standardised active, guided movements, as performed by the MOBID procedure, is a useful means of arriving at reliable and valid pain intensity scores in patients with severe dementia.

II Pain behaviour and pain intensity in older persons with severe dementia: Reliability of the MOBID Pain Scale by video uptake

Husebo BS, Strand LI, Moe-Nilssen R, Husebo SB, Ljunggren AE

Scandinavian Journal of Caring Science2008; in press.

Background: Advancing age is associated with a high prevalence of dementia, often combined with under-diagnosed and under-treated pain. The nurse-administered Mobilization–Observation–Behaviour–Intensity–Dementia Pain Scale (MOBID) has been developed in order to unmask pain during standardised active, guided movements.

Objectives: To examine the extended intra-rater and inter-rater reliability of pain behaviour indicators, inferred pain intensity and the overall pain score.

Methods: Twenty-six nursing home patients with severe dementia and chronic pain were guided by their primary caregivers to perform standardised active, guided movements using MOBID while being video recorded. Three external raters assessed the video recordings with respect to pain behaviour indicators (Pain noises, Facial expression, Defence) inferred pain intensity and the overall pain score, concurrently and independently, on day 1, 4 and 8.

Results: Facial expression was most commonly observed, followed by pain noises and defence. The number of observed pain behaviours increased on repeated assessment, but this did not improve reliability. Inter-rater reliability was highest for noises, followed by defence and facial expression (κ=0.44-0.92, κ=0.10-0.76 and κ=0.05-0.76, respectively, on day 8). The mobilisation of arms and legs was rated most painful. The intra-rater and inter-rater reliability of overall pain was very good (ICC 1,1 ranging from 0.92 to 0.97 and 0.94 to 0.96, respectively). As opposed to pain behaviour, the reliability of pain intensity scores tended to increase on repeated assessment.

Conclusion: Using video recordings, the MOBID Pain Scale was shown to be sufficiently reliable to assess pain in older persons with severe dementia.

III Pain in older persons with severe dementia. Psychometric properties of the Mobilization–Observation–Behaviour–Intensity–Dementia (MOBID-2) Pain Scale in a clinical setting

Husebo BD, Strand LI, Moe-Nilssen R, Husebo SB, Ljunggren AE. Under review.

Background: In order to assess pain in older persons with severe dementia, a two-part nurse-administered observational instrument, the Mobilization-Observation-Behaviour-Intensity-Dementia (MOBID-2) Pain Scale, was constructed and its psychometric properties tested by primary caregivers in a clinical setting.

Objectives: In MOBID-2, the assessment of inferred pain intensity is based on patients' pain behaviour in connection with the standardised, guided movement of different body parts (Part 1), and pain behaviour related to internal organs, the head and skin registered on pain drawings and monitored over time (Part 2).

Methods: Patients with severe dementia (N=77) were examined by 28 primary caregivers, who concurrently and independently completed the MOBID-2. Characteristics of the patients' pain were also investigated by their physicians (N=4).

Results: The prevalence of any pain was 81%, with predominance in the musculoskeletal system, highly associated with the overall pain score (rho=0.82). Most frequent and painful was the mobilisation of the legs. Pain in the pelvis and/or genital region was frequently observed. Good to very good inter-rater and test-retest agreement was demonstrated for pain behaviour and pain drawings (κ = 0.41-0.90 and κ = 0.46-0.93), as well as for pain intensity (ICC (1,1) ranging from 0.80 to 0.94 and 0.60 to 0.94, respectively). Internal consistency was highly satisfactory (α= 0.82-0.84). Face-, construct- and concurrent validity were good. Overall pain intensity as measured by MOBID-2 was well correlated with physicians' clinical examinations of pain and defined pain variables (rho=0.41-0.64).

Conclusion: The MOBID-2 Pain Scale was shown to be sufficiently reliable, valid and time-effective for nurses to assess the localisation, behaviour and intensity of pain in patients with severe dementia.

IV Who suffer most? Dementia and pain in nursing home patients: A cross-sectional study

Husebo BS, Strand LI, Moe-Nilssen R, Husebo SB, Aarsland D, Ljunggren AE.
Journal of the American Medical Directors Association 2008; in press.

Background: The Mobilization–Observation–Behaviour–Intensity–Dementia (MOBID-2) Pain Scale is a novel staff-administered pain tool, developed to assess the location, behaviour and intensity of pain in patients with severe dementia.

Objectives: To explore pain in NH patients and to compare pain relating to different stages of dementia, different dementia diagnoses and use of pain medication.

Methods: In a cross-sectional study, 181 consecutive, long-stay nursing home patients were assessed by their 43 primary caregivers, and four physicians. Admission records, prescription lists, care plans, Mini-Mental State Examination, Statistical Manual of Mental Disorders (DSM-IV), international classification of diseases (ICD-10), cerebral computer tomography, pain diagnoses and pain locations from physicians' examinations, and pain intensity measured by MOBID-2 were recorded.

Results: Patients with severe dementia do not experience less pain intensity (P= 0.079), pain diagnoses (P=0.172) and pain locations (P=0.202) compared with other stages of dementia. The severely demented patients, who received opioids, demonstrated higher pain intensity (mean 4.4, SD 1.7) than non-demented patients (mean 2.9, SD 1.8) (P=0.018), and they received less pain treatment. Pain intensity did not differ between diagnostic groups of dementia (P=0.439). Patients with mixed dementia who received opioids had more pain (mean 5.3, SD 1.5, range 4-7) than mentally healthy controls (P<0.005) and they received less pain treatment.

Conclusion: Patients with different levels and diagnoses of dementia demonstrated the same degree of pain characteristics and need for pain medication as non-demented patients, but had a higher number of ICD-10 diagnoses. The findings suggest that a comprehensive approach to pain treatment in a multidisciplinary perspective is required.

MAIN FINDINGS AND SYNOPSIS OF THE PAPERS

The most important findings of this thesis are:

- Standardised active, guided movements of all body parts as assessed by the MOBID Pain Scale and the MOBID-2 Pain Scale Part 1 seem to be of high clinical significance with respect to capturing movement-related musculoskeletal pain based on defined pain behaviour indicators and inferred pain intensity scores (**Paper I**).
- The internal consistency of the MOBID Pain Scale measured by a high Cronbach's α=0.90 was arrived at after deleting the items 'at rest' and of 'teeth/mouth care' (**Paper I**).
- Facial expression was the most commonly observed pain behaviour indicator, followed by pain noises and defence (**Paper I**). Inter-rater reliability was highest for noises, followed by defence and facial expression (κ=0.44-0.92, κ=0.10-0.76, and κ=0.05-0.76, respectively, on day 8) (**Paper II**).
- The inter-rater and intra-rater reliability for inferred pain intensity for each MOBID item and the overall pain score were very good, ICC(1,1) ranging from 0.92 to 0.97 and 0.94 to 0.96, respectively, on day 8. The reliability of pain intensity scores tended to increase on repeated assessment (**Paper II**).
- The internal consistency of MOBID-2 was highly satisfactory (Cronbach's α=0.82-0.84). Moderate to excellent agreement was demonstrated for pain behaviour and pain drawings (κ=0.41-0.90 and κ=0.46-0.93, respectively). Inter-rater and test-retest reliability for pain intensity was very good (ICC1,1=0.80-0.94 and 0.60-0.94) (**Paper III**).
- Through primary caregivers using MOBID-2, 64% of patients were found to have pain defined as NRS$\geq$3.
- MOBID-2 pain scores demonstrated a predominance in the musculoskeletal system. Mobilisation of arms and legs was rated most painful (**Paper III**).
- Pain probably originating from the pelvis and/or the genital organs was frequently observed as pain from internal organs (**Paper III**).
- Indicating concurrent validity, pain intensity scores measured by the MOBID-2 Pain Scale were associated with the number of pain diagnoses, locations of pain, analgesic treatment and physicians' pain scores using the NRS (**Paper III**).
- Both Part 1 and Part 2 of the MOBID-2 Pain Scale correlated satisfactorily with the overall pain score, Part 1 most (rho=0.82), suggesting that pain behaviour occasioned by

standardised movements may represent a more concrete pain concept than the observation of pain from internal organs, the head and skin (rho=0.61) (**Paper III**).

- Patients with severe dementia neither experienced less pain intensity nor had fewer diagnoses and locations of pain than those with moderate, mild and no dementia (**Paper IV**).
- Patients with severe dementia who received opioids as pain treatment were assessed as having higher pain intensity than non-demented persons receiving opioids (**Paper IV**).
- Pain intensity did not differ in diagnostic groups of demented patients compared with non-demented patients, but those with ADVaD who received opioids tended to have higher pain intensity than non-demented persons receiving opioids (**Paper IV**).
- Findings suggest that NH patients demonstrate a complex picture of suffering, including a high number of diagnoses and, possibly, under-treatment of pain, especially in the case of severe dementia and ADVaD (**Paper IV**).
- The findings of this study provide evidence for the reliability and validity of the newly developed MOBID-2 Pain Scale for patients with dementia, and demonstrate that this scale can be used reliably in a clinical NH setting (**Papers I- IV**).

DISCUSSION

GENERAL CONSIDERATIONS

It was the aim of this thesis to develop a nurse-administered instrument to assess pain in patients with dementia and to examine whether this scale is reliable and provides arguments for validity. As highlighted in reviewed studies and in this thesis, without a gold standard, the validation process for a pain scale is challenging (Stolee et al., 2005; Herr et al., 2006; Zwakhalen et al., 2006b; Hadjistavropoulos et al., 2007). Moreover, the testing of validity is not only seen as demonstrating the psychometric properties of a scale, it also emphasises the characteristics of the people who are assessed (Cronbach, 1971). In this chapter, methodological strengths of and limitations on the development and testing of psychometric properties of the Mobilization-Observation-Behaviour-Intensity-Dementia (MOBID-2) Pain Scale are summarised. The extent to which the limitations have influenced the results is discussed in connection with the use of this new scale in a cross-sectional study.

METHODOLOGICAL CONSIDERATIONS

Reliability, internal consistency

In **Paper I**, Cronbach's α for the initial MOBID procedure, including seven items assessed by different raters, ranged from 0.86 to 0.89. When the items 'at rest' and 'teeth/mouth care' were deleted from observation of the patient, Cronbach's α increased, ranging from 0.90 to 0.91. The internal consistency of the comprehensive MOBID-2 Pain Scale (**Paper III**) demonstrated a lower Cronbach's α coefficient (α=0.82-0.84). The items for the head and skin showed a lower item-total correlation, between 0.20 and 0.35, and it was considered whether they should be discarded from the tool. However, using the normal rule of thumb formulated by Streiner and Norman, (2006), the items were retained since they had the correct item-total correlation of about at least 0.20. These items were seldom scored, with little spread in pain intensity and thereby little impact on the α-value. Furthermore, it was considered important to register pain from all body parts. The internal consistency of the MOBID-2 items can also be discussed in light of content or construct validity, which is demonstrated through logical presentation of relevant elements (content) of the attribute

(pain) being measured (Rothstein and Echternach, 1993). Internal consistency may thus add arguments for the selection of relevant elements used to assess pain.

Reliability of pain behaviour

In **Papers I-III**, the intra-rater, inter-rater and test-retest reliability of pain behaviour indicators were analysed by kappa (κ) statistics. Facial expression was the most frequent pain behaviour demonstrated, followed by pain noises and defence. Whereas moderate to very good κ-values were demonstrated for pain noises, the inter-rater reliability for facial expression and defence varied between poor and excellent. The analyses in the present study were very detailed with respect to both intra-rater reliability and inter-rater reliability, each pain behaviour indicator relating to every guided movement being investigated. Usually, pain scales assess the occurrence of individual pain behaviour indicators, not related to tasks performed. The minute registration involved provides detailed information, which is important if patients are to be given adequate treatment. On the other hand, this means that reliability is lower than in previous instruments, where ratings are generally coarser. Our results also emphasise the caregivers' interpretation of what pain means to the patient. To observe behaviour is important, but its interpretation and conversion into pain intensity is of prime importance. It should always be considered and stressed that behaviour may also be caused by psychiatric disorders related to dementia

The intra-rater reliability of pain behaviour indicators did not increase on repeated measurement (**Paper II**), and κ-values were actually somewhat lower during test-retest examination (**Paper III**). Domholdt (2005) emphasised the challenge of reproducing measurements of pain, because pain is a changing phenomenon. Comparing the assessment of pain behaviour indicators during video recordings with bedside examination, it was unexpectedly found that nurses observed less pain behaviour in a clinical setting, but obtained good inter-rater reliability and even better test-retest reliability (**Papers I-III**). This makes sense, because the 'hands on' situation and the patient-caregiver dyad at the bedside may have a central impact on the individual's interpretation of pain behaviour. Several studies used video recordings to validate the psychometric properties of pain assessment instruments (Snow et al., 2004b; Defrin et al., 2006; Zwakhalen et al., 2006b). One can speculate, however, that scoring by video recording overestimates pain observations, or that 'hands on' situations underestimate them. Further research is needed to determine which testing situation is most valid.

Reliability of pain intensity

In **Papers I-III**, the intra-rater, inter-rater, and test-retest reliability of pain intensity of each MOBID and MOBID-2 item, as well as the overall pain intensity, were analysed using ICC(1,1) statistics. Each aspect of the analysis demonstrated high to excellent reliability of pain intensity in the MOBID and the MOBID-2 Pain Scale, both using video recordings and during bedside examinations. In connection with the challenge of judging pain from internal organs and the skin, the MOBID-2 Part 2 demonstrated somewhat lower reliability scores. In addition, lower test-retest values reflect the fact that a second cause of variability is introduced, when the test is repeated over time, simply due to a change in pain, a change in the test situation or in the mood of the patient (Domholdt, 2005). We concluded in **Papers I-III** that there may be a connection between the actual observation and the interpretation of the whole care situation. This confirms earlier results that the observer must be familiar with the patient and his usual behaviour (Morello et al., 2007). Reviews of pain assessment scales for persons with dementia have to be interpreted in the context of the patient-proxy dyad, and observations at rest or during activities. Such examinations may give rise to or alleviate pain, and behaviour may be typical of pain, but also of dementia. Some existing scales investigate reliability in terms of pain behaviour, others in terms of intensity, while yet others combine both. We found no studies explicitly distinguishing between observed pain behaviour and pain intensity, as is the case in the present thesis.

Our findings demonstrate a number of other, more subtle elements of the pain communication process. We found that reliability was particularly high in the overall score of pain intensity, but it was also satisfactory for the individual movements. However, the reliability of the pain behaviour indicators was not generally high. This seems to contradict the idea that high reliability of pain behaviour indicators is a prerequisite for adequate reliability of inferred pain intensity. It is considered most important to discover whether the patient is in pain and also where it hurts in order to begin a process of treating the pain. Perhaps the intensity of pain behaviour, rather than the number of pain behaviours, is most important as a basis for scoring pain intensity. The importance of the specified pain behaviours may simply be that it increases awareness of pain expressions.

Reliability of pain drawings

As a central part of any thorough pain evaluation, pain drawing is the instrument most commonly applied to register pain location (Jensen and Karoly, 2001). Moderate to high reliability of pain drawings has previously been demonstrated in cognitively intact people (Margolis et al., 1988). MOBID-2 is the first pain scale for demented persons where proxies are encouraged to use a pain drawing to suggest the location of pain, based on behavioural observations. In **Paper III**, about 40% of the raters documented their observations on pain drawings. The highest number of crosses for pain was observed in the pelvis and genital organs, and lowest for the skin. Moderate to good inter-rater reliability was shown for pain drawings, as well as good test-retest reliability, particularly for the pelvis and genital organs.

Validity

One of the most difficult aspects of validity testing is the terminology, including face validity, construct, and concurrent validity (Streiner and Norman, 2006). There is no simple, absolute, direct test of validity, and there is a risk of thinking of a measurement as being either valid or invalid. Almost all measurements contain some information. The word (concept) validity is not an all-or-nothing concept. Research evidence can add arguments for validity, but it can never directly or absolutely test whether all relevant elements are reflected in the measurement (Rothstein and Echternach, 1993). The validity of a pain measurement has to be debated, particularly, in the case of a proxy rating a demented patient's pain problems. Given the lack of alternative measurements, this approach is an important one.

Validity of the MOBID-2 items

As patients tend to avoid painful movements, an approach involving obligatory, standardised active, guided movements adds new and important aspects to the assessment of pain in dementia. In line with our presumption, higher overall pain scores ($p<0.005$) were registered using the MOBID procedure than after regular care activities (**Paper I**). Support was thus provided for construct validity. Other pain scales such as the CNPI, ADD, Doloplus-2, NOPPAIN and ECPA encourage the raters to observe the patient during everyday activities. However, since these measures do not require a standardised movement protocol, pain

behaviour may not be revealed, as pain tends to change the way activities are performed (Magnussen et al., 2004). Patients may even avoid moving completely if it hurts.

The use of active, guided movements was debated during development of the MOBID Pain Scale, as this approach may be more pain-provoking than naturally occurring activities. The presence of pain contributes to a pain circle, in which less mobilisation of the patient causes muscle hypotrophy, contractures and often more pain. The ethics of the primary caregivers provoking pain may be questioned. The aim of the MOBID or the MOBID-2 procedure is not to provoke unnecessary pain, but to identify the problem. The pain-provoking movement is reversed immediately whenever pain behaviour is perceived. In this way staff may contribute to revealing pain in demented patients, which is a prerequisite for pain management.

With respect to face validity (**Paper I**), the focus group requested that items should not only be related to the musculoskeletal system, but also to visceral and neuropathic pain and headache syndromes. As one of the first pain scales for patients with dementia, MOBID-2 Part 2 included the assessment of behaviour that might be related to pain from internal organs, the head and skin (**Paper III**). The focus group underlined that the judgement of a demented patient's pain experience will always be challenging, especially when pain stems from the head, internal organs and skin. Caregivers are neither skilled nor authorised to investigate these areas. In order to capture such pain, the observation of pain behaviour should probably be monitored by the caregivers over time. It should be a prerequisite that the rater is familiar with the patient's usual behaviour. The focus group maintained that MOBID-2 seemed well-suited to identifying the prevalence of pain related to the musculoskeletal system and internal organs by a caregiver who knows the patient.

The ADD and the Abbey pain scales encourage the rater to assess pain from internal organs. These scales are not based on defined pain behaviour, do not include skin problems, which are frequent health problems in the NH, and do not discriminate between pain from the musculoskeletal system and other types of pain. Investigating construct validity, it was demonstrated that items in both Part 1 and Part 2 were satisfactorily correlated with the overall pain score. However, MOBID-2 Part 1 items were more highly associated with the overall pain intensity scores (rho=0.82) than Part 2 items (rho=0.61). This makes sense because the prevalence of nociceptive pain (NRS≥3=58%) was more frequently observed than pain probably originating from internal organs or the skin (NRS≥3=42%) (**Paper III**). Moreover, pain behaviour caused by standardised movements may cause a more immediate

pain reaction than the pain behaviour emanating from internal organs, the head and skin, monitored over time.

One major consideration in item selection is the desire for specificity versus sensitivity. MOBID-2 is a time-effective pain scale that includes 10 items. It was considered by the focus group to be relevant, manageable, motivating and feasible for staff in a clinical setting. Shorter tools include limited indicators, but, if present, they may be more likely to accurately recognize pain. Longer and more comprehensive instruments are also recommended, possibly capturing more pain behaviour, although some patients may be identified whose behaviour is not caused by pain (Hadjistavropoulos et al., 2007). In a validation study of PACSLAC, DOLOPLUS-2, and PAINAD, caregivers judged the PASCLAC to be clinically useful (Zwakhalen et al., 2006b). However, to answer 60 questions in five minutes seems to be challenging the case of patients with dementia. Time-consuming assessments and personal compliance is little discussed in the context of stressful NH routines, but feasibility is mandatory for an assessment tool to be used in the clinic.

Validity of pain behaviour

The MOBID and MOBID-2 Pain Scale include three key indicators of pain behaviour (Pain noises, Facial expression, Defence) accompanied by 12 explanatory words. In **Paper I-III**, facial expression was the most frequently observed pain behaviour indicator, followed by pain noises and defence. The number of observed pain behaviours (independent variable) was shown to significantly influence the staff's interpretation of pain intensity (dependent continuous variable) ($p<0.005$). When no pain behaviour was observed, no pain intensity was registered, while an increasing number of pain behaviour indicators caused increased pain intensity scores with a linear trend (**Paper I**). Another aspect of construct validity was indicated, as the overall pain intensity scores measured by the MOBID Pain Scale were shown to be higher when scored from video rating than from bedside observation ($P<0.001$), although the scores were highly correlated ($r_s=0.67$). The results underline that important pain behaviour indicators may be overlooked during bedside observation. It was unexpectedly found that the maximum pain intensity scores among all the MOBID items demonstrated a higher correlation with the overall pain intensity ($r\geq.92$) than the mean pain intensity of all items ($r\geq.86$). This makes sense, as it is probably less important for a patient to be pain-free in, e.g. his knees when he is struggling with serious back pain, because the back pain will dominate his overall pain experience.

The interpretation of pain behaviour indicators is challenging. According to Ekman and Friesen (1982), observers are able to discriminate between seven facial expressions of emotion. In this list, pain is not included as an isolated and unique expression, but is related to the expression of fear (Ekman, 1993). As such, fear may be an indicator of both psychological challenge and pain. Thus, questions could be raised about the sensitivity and specificity of facial expression for the purpose of pain assessment. Furthermore, several indicators of pain, such as restlessness, depression, isolation and aggression, can be observed in connection with behavioural disturbances caused by dementia. In the absence of a gold standard, this methodological challenge has been discussed in recent years. The earliest attempts to quantify pain using behavioural observation suggested that a protocol should be followed in which patients were asked to perform a series of behaviours during which they were videotaped (Keefe and Block, 1982). Raters then scored the presence or absence of specific behaviour in timed sequences. Such approaches are cumbersome in a clinical setting, but very useful for research purposes in relation to testing the reliability and validity of a behavioural tool.

To examine the validity of a behavioural pain scale, the total scores of previously developed instruments were correlated with a visual analogue scale (VAS) or other intensity scale filled in by a proxy. However, we could not find previous reports with detailed validity testing of separate pain behaviour indicators, as performed in **Paper I**. This is of key importance, since patients with dementia may not present any pain behaviour caused by physical impairment. On the other hand, pain influences behavioural disturbances among those with severe dementia more often than among those with moderate or mild dementia, and residents with chronic pain who have severe dementia exhibit significantly more dysfunctional behaviour than those with earlier-stage dementia (Cipher et al., 2006). It remains to be seen whether, instead of using a proxy report approach, it could be an option to use a selected group of elderly people with the ability to self-report their pain, as an alternative strategy aimed at further validating behavioural indicators. However, the scoring of pain behaviour indicators depends largely on the proxy rater's awareness of pain, which may be a useful option.

We did not include more subtle non-verbal indicators, such as changes in interpersonal interaction, mental status, activity patterns and routines, as recommended by the American Geriatrics Society (1998). While considered interesting, we question whether it is possible to distinguish between psychiatric disturbances related to dementia, pain behaviour and behavioural changes. Functional items such as sleep, appetite and social contact are affected

by pain, but they may also depend on a large number of other factors. Rare use of these items has been demonstrated, as well as low reliability and validity (Holen et al., 2005; Zwakhalen et al., 2006b).

Validity of pain intensity scores

Norm referencing may be another aspect of validity. It describes how a scale relates to a correct judgement from a representative sample of the population (Rothstein and Echternach, 1993). In the MOBID and MOBID-2 Pain Scale, a new concept was presented, as observed pain behaviours were inferred to pain intensity. This interpretation of whether behaviour is related to pain or dementia also reflects the observers' individual experience and attention. The most frequently occurring, and with highest pain intensity, was mobilisation of the legs, in line with the diagnosis from the patients' medical records. This is also in line with primary health care studies, where pain related to knees and shoulders is considered to be a frequent complaint (Mantyselka et al., 2001), as is pain from the pelvis/genital organs and irritable bowel syndrome (Chaplin et al., 2000). However, cardiovascular disorders, a frequent health problem in the elderly (Crepaldi and Scognamiglio, 2000), were seldom assessed by the MOBID-2 Pain Scale. This may be explained by a defective ischemia warning system or lack of typical symptoms in connection with angina pectoris (Cohn et al., 1999). In MOBID-2 Part 2, the observation of pain behaviour monitored over time (today or during the last few days, week) is recommended. Perhaps a more detailed description of pain behaviour related to internal organs, the head and skin would be a better concept. However, the expression of pain related to these areas is individual, depending on the nature and duration of pain.

In **Paper III**, support was provided for the concurrent validity of the MOBID-2 Pain Scale, as there was an association between the overall pain intensity assessed by nurses and other pain variables (number of pain diagnoses, pain locations and pain medications) assessed by physicians. Furthermore, the overall MOBID-2 pain intensity scores were related to the intensity score assigned by physicians using the NRS. These are satisfactory results, as these measures represent different aspects or indicators of pain intensity. **Paper IV** also provided arguments for concurrent validity, as pain characteristics and baseline measurements were compared between groups of pain medication and pain diagnoses (P=0.001), pain localisations (P=0.001), MOBID-2 overall pain intensity (P=0.001), Part 1 (P=0.001) and Part 2 (P=0.001).

The use of the 0-10 numerical rating scale (NRS) to rate the pain intensity of each MOBID-2 item and the overall pain scores can be debated, as no information has been published about the distribution of its measurement error (Williamson and Hoggart, 2005). This scale is a well accepted disease-specific measure of pain intensity and it has been used successfully in a number of recent chronic pain drug studies (McQuay, 2005). In addition, the NRS has been found to be very responsive to changes in pain, even more so than the VAS. The satisfactory responsiveness to change indicates that its measurement error is within acceptable levels (Bolton and Wilkinson, 1998).

Validity of pain drawings

Caution must be exercised not to over-interpret pain drawings from proxy raters in patients with dementia. As pain from internal organs, the head and skin may be difficult to identify, and caregivers are not authorised to perform clinical examinations, one main effect of pain drawing could be to increase the caregivers' awareness of the patient's pain. Only simple crosses were used to suggest pain location in the present study. In cognitively intact people, shading the area of pain extension would provide better information. To obtain more detailed boundaries for pain extension via proxies seemed unrealistic. It may be difficult to discriminate between pain originating from the abdomen or the pelvis. Merging these two items could simplify the scoring. Furthermore, 19% of the assessed patients had marks on pain drawings related to the musculoskeletal system, especially the extremities (**Paper III**). In connection with scoring MOBID-2 Part 1, raters may still be focused on these pain sites, and therefore also mark the observed pain on the body chart. Moreover, referred pain from internal organs (e. g. heart, gallbladder, bladder) may stimulate corresponding dermatomes (Nurmikko, 1995; Higa et al., 1997; Petchkrua and Harris, 2000; Inoue et al., 2006). Unfortunately, research into the projection of pain from visceral diseases onto pain dermatomes is rare in elderly people with dementia.

THE MOBID-2 PAIN SCALE IN A CLINICAL SETTING

After the psychometric property testing of the MOBID-2 Pain Scale (**Paper I-III**), the pain scale was used to test the hypothesis that the amount of pain characteristics (diagnoses, location and intensity of pain) and pain medications decreases as levels of dementia increase, and that pain intensity differs between subjects with different dementia diagnoses (**Paper IV**). These hypotheses were based on studies suggesting that patients' ability to report pain decreases as cognitive impairment increases (Huffman and Kunik, 2000), and that patients with dementia may experience less pain perception and higher tolerance of experimental pain (Scherder et al., 2001; Benedetti et al., 1999).

Contrary to the hypothesis, we found that pain characteristics and the number of pain medications were not associated with the severity of dementia. Patients with severe dementia neither experienced less pain intensity nor had fewer diagnoses and locations of pain than those with moderate, mild and no dementia. In addition, pain intensity did not differ in diagnostic groups of demented patients compared with non-demented patients. Indeed, patients with severe dementia and ADVaD who received opioids tended to have even higher pain intensity scores as measured by the MOBID-2 Pain Scale than non-demented persons receiving opioids.

These results are consistent with those of Cole and colleagues (Cole et al., 2006) who found that AD patients showed greater amplitude and duration measured by functional brain imaging than controls, as a response to noxious stimuli. It was also suggested that disruption caused by white-matter lesion may increase pain experience by deafferentiation in patients with VaD compared with AD (Melzack, 1999). Pain experience involves many pain components related to the lateral and medial pain system. These areas may be affected in AD and VaD, leading to changes in pain processing (Scherder et al., 2003b; Scherder et al., 2002; Scherder et al., 2003a). In contrast to acute pain caused by stimulation during fMRI performance, elderly patients suffer from chronic pain (Miro et al., 2007), which is associated with decreased regional cerebral blood flow (Peyron et al., 2000). It remains a key question whether results from fMRI can be transferred to clinical observations and individual consequences for the individual patient.

Our data strongly suggest that patients with ADVaD are more distressed by increased pain intensity than are non-demented patients. One possible explanation for this may be that infarction of the brain may occur in many locations and influence all dimensions of pain (Scherder et al., 2003a). A high prevalence of pain combined with communicative

disabilities may therefore lead to a despairing situation for these patients. Cipher and colleagues (2006) suggested that pain influences behavioural disturbances among those with severe dementia more often than among those with moderate or mild dementia, and residents with chronic pain who have severe dementia exhibit significantly more dysfunctional behaviour than those with earlier-stage dementia (Cipher et al., 2006).

If pain experience is increased in mixed and severe dementia, the reduced prescription of pain medication (Morrison and Siu, 2000; Frampton, 2003; Nygaard et al., 2003; Nygaard and Jarland, 2005; Hutt et al., 2006) and the potential reduced effect of such drugs in patients with dementia (Benedetti et al., 2006) would mean that pain is undertreated, resulting in increased suffering in this frail population. In the present study (**Paper IV**), the total number of pain medications did not differ according to different levels of dementia and dementia diagnoses, suggesting a comparable need for pain treatment. The reason why patients with severe dementia (24%) and ADVaD (9%) did not receive the same amount of opioids as non-demented elderly persons (37%) could be a wish to avoid side effects (Pickering et al., 2001). Older people are more likely to experience the side effects of analgesic medications, and they appear to be more sensitive to analgesic properties, especially those of opioid analgesics (Dahl, 1996; Pickering et al., 2001). However, we found no studies investigating opioid side effects in patients with dementia.

Our results may also be explained by the staff's over-interpretation. Care providers who are interested in pain assessment in dementia and have long work experience participated in this study. To assess a patient's pain and observe him while interpreting pain behaviour is demanding and may be a psychological burden. Visual impressions of patients' suffering may lead to increased pain intensity scores. The fact that this NH has a palliative care unit with physicians and caregivers skilled in pain treatment might have influenced the findings. The use of opioids in general did not seem to be restricted, since a high percentage of mentally healthy controls received opioids as pain treatment. The fact that patients with ADVaD, in particular, received less opioids may be due to the fact that it is difficult to capture pain behavioural expressions in this group of patients. It does not seem to be sufficient to be generally competent in pain assessment and treatment; competence should also include pain in dementia.

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Pain assessment in dementia is complex, but the patients' pain characteristics and need for pain relief seem to be comparable with mentally healthy controls. At all levels of dementia and in VaD and ADVaD, the increased prevalence of ICD-10 diagnoses may contribute to increasing the patients' suffering. We suggest that patients received less pain relief than they needed, and that an isolated increase of opioids may be limited by a high prevalence of ICD diagnoses and opioid side effects. The patients' multi-morbidity and lack of communicative ability suggest the need for a comprehensive approach to pain assessment and treatment in a multidisciplinary perspective. More research and quality improvement programmes are needed regarding pain assessment and pain management in dementia.

The classification of dementia etiology groups was based on physicians' clinical examinations, screening of dementia and cCT. This classification may be attenuated by underlying subtle brain processes which can only be clarified by autopsy.

CHRONIC VERSUS ACUTE PAIN

It may be a limitation of this thesis that a differentiation has not been accomplished between acute and chronic pain behaviour. Such differentiation is normally of key importance, since the duration of pain has a high impact on the expectation of pain treatment (Turk and Okifuji, 1999), and 94% of elderly persons with pain in the Mediterranean region of Catalonia experience chronic pain (Miro et al., 2007). Breivik et al. (2006) demonstrated an overall prevalence of moderate to severe chronic pain in the general adult population of 15 European countries and Israel of 19%. About 40% of the respondents suffering from chronic pain were not satisfied with the effect of treatment. Many aspects of everyday life, working life, somatic, emotional and social wellbeing were described to be affected (Breivik et al., 2006). However, the oldest, the sickest, and those living in NHs were not included in this survey (Breivik et al., 2006).

It is a challenge to choose a pain stimulus which provides an opportunity to observe patients with a reasonable level of pain. Acute pain stimulation in the form of influenza vaccination has been used to test existing pain assessment instruments (Defrin et al., 2006; Zwakhalen et al., 2006b). Such a model will test acute pain, but lack relevance to clinical situations for cognitively impaired patients with chronic pain in NHs. Future research must investigate relevant methodological approaches, and whether acute pain behaviour during vaccination stimuli is congruent with chronic pain behaviour provoked by standardised movements.

Further research is also needed to investigate the responsiveness of the MOBID-2 Pain Scale, which is an important issue in terms of reflecting changes in pain experience after treatment. Responsiveness is related to both the reliability and validity of the measure. If a measure is not very reliable, then changes in scores must be large if they are to represent more than measurement errors (Domholdt, 2005). Such a study should include an open systematic pain medication study (with respect to dementia) as well as different treatment routes (e.g. antibiotics, nitro-glycerine) (Cohen-Mansfield and Lipson, 2007).

EXTERNAL VALIDITY

External validity deals with the possibility to generalize the test results of the MOBID-2 Pain Scale to other populations than participants of the present study (Domholdt, 2005). Our findings are based on data from only one NH, and external validity regarding other NHs might be questioned, as pain assessment, pain treatment and conditions for the staff may be

different. As most of the patients were admitted to the NH from primary health care and hospitals, patients included in the study could reflect the frequency of pain problems in elderly patients in general. The fact that the included patients were admitted to the NH, indicated that they were more severely ill than patients in the same age with the same diagnoses treated at home. Compared to them, NH patients may have more clinical risk factors, for instance immobility caused by stroke, and thus a higher probability of having pain. Therefore, one should be cautious about general extrapolation of the study finding to primary care. In addition, a more severely ill patient might also be expected to develop more drug-related interactions related to opioid analgesics or NSAIDs.

The psychometric properties of the MOBID and the MOBID-2 Pain Scale were tested in patients with severe dementia. Additionally, the MOBID-2 was used to assess the behaviour, intensity, and location of pain in patients with different levels and diagnoses of dementia in a clinical setting (**Paper IV**). We did not examine the usefulness of the scale regarding patients with moderate and mild dementia, or dying patients with reduced consciousness. This should be of future interest, as a systematically approach of the MOBID-2 Pain Scale may be of interest in these patients.

ETHICS AND APPROVALS

The process of obtaining ethical approval from the responsible Norwegian government body in accordance with applicable legislation for including patients with dementia in this study was a laborious one, although of key importance. According to the Declaration of Helsinki, the approval of a research ethics committee is needed for every scientific study on patients (Carlson et al., 2004). There has to be a balance between the obligation to protect the patient, on the one hand, and the possibility of increasing patients' quality of life through new research results, on the other.

Special precautions are necessary in connection with research on patients with cognitive impairment, if they are judged to be potentially incapable of consenting (Margiotta et al., 2002). For a research subject who is under legal guardianship, pursuant to applicable legislation, the investigator must obtain informed consent from the legally authorised representative in accordance with applicable law. Generally, mentally incompetent people should not be included in research unless the research is necessary in order to promote the health of the population represented, and this research cannot be performed on legally

competent persons. Moreover, research on individuals from whom it is not possible to obtain consent should only be performed if their physical and mental condition is a necessary characteristic of the research population.

As regards studies in patients with dementia, researchers themselves play a particularly important role, because they have to judge whether or not a potential participant is capable of consenting. Research has shown that the diagnosis of dementia does not necessarily mean that a patient is incapable of making a decision about not to take part in a clinical study (Karlawish et al., 2002). Across Europe, the protection of research subjects with dementia has to satisfy a variety of national legalisation and ethical codes. Including 12 countries, one study demonstrated the differences in strategies between medical ethical committees with respect to informed consent and capacity to consent (Rikkert et al., 2005).

As is the case in researching a good death, practical, ethical and methodological difficulties have to be overcome. Kendall and colleagues (2007) concluded that many patients approaching the end of life wish to participate in research, because research can enrich the lives of participants and enhance the dignity of patients. Patients with severe dementia would seem to be incapable of giving informed consent to participation in a research study, and they have to be protected against research projects that might be harmful (Margiotta et al., 2002). However, the lack of openness in society about attitudes to ageing and dementia may act as a barrier to dementia research, leading to the exclusion of these patients. Yet such research is essential. The research process must be conducted with ethical and methodological rigour and in ways that support the patients, their relatives, and the staff. Committees of ethics and clinicians must balance their concerns about non-maleficence against presumed consent by relatives or the autonomy of people to participate if they wish.

SUMMARY AND CONCLUSION

In most countries, the population of individuals over the age of 65 years is increasing, and thereby the prevalence of dementia. Advancing age is also associated with increased prevalence of pain, often caused by musculoskeletal conditions, pain from internal organs or neuropathies. Thus, many elderly, living at home or in long-term care settings, experience both dementia and pain. The measurement of pain in these patients remains a challenge, caused by a decreased or absent capacity to self-report due to deficits in language, memory, and abstract thinking inherent to this disease.

The Mobilization-Observation-Behaviour-Intensity-Dementia (MOBID-2) Pain Scale is a two-part nurse-administered observational instrument aimed at assessing pain in patients with dementia. In MOBID-2, inferred pain intensity is based on patients' pain behaviour during standardised, guided movements of different body parts (Part 1), and pain behaviour related to internal organs, the head and skin (Part 2). Internal consistency measured by Cronbach's alpha was highly satisfactory. The inter-rater and test-retest reliability for pain intensity was very good. Arguments for face-, construct- and concurrent validity were provided, as MOBID-2 pain scores were correlated with physicians' examinations and other parameters of pain.

Using MOBID-2 in a cross-sectional study, pain characteristics and the number of pain medications were not found to be associated with severity of dementia. Patients with severe dementia neither experienced less pain intensity nor had fewer diagnoses and locations of pain than those with moderate, mild and no dementia. Patients with severe dementia and ADVaD who received opioids as pain treatment were assessed as having higher pain intensity than non-demented persons receiving opioids.

It was concluded that pain assessment in dementia is a complex issue. The judgement of a demented patient's pain experience by a proxy rater will always be challenging, especially when the pain stems from the head, internal organs or skin. Certainly, the validity of pain intensity scores can be questioned, and they should be substantiated by physicians who can perform thorough examinations. Finally, the results of this thesis are based on data from only one NH, and external validity in relation to other NHs must be examined in future research, since pain assessment, pain treatment and conditions for the staff may be different.

IMPLICATION AND FURTHER RESEARCH

The development and psychometric property testing of the MOBID-2 Pain Scale has not yet been accomplished. The following steps will be included in future research:

1. examining the usefulness of the instrument in assessing acute as well as chronic pain, related to pain duration
2. further assessing the concurrent validity of the MOBID-2 by comparing the scale with other pain scales for patients with dementia
3. investigating the responsiveness of the scale in an open intervention study
4. using MOBID-2 in different clinical settings

When working with the concept of MOBID-2, we experienced that healthcare professionals showed an interest in the framework and results of this thesis. Both standardised training in pain assessment and treatment in dementia and the translation and testing of the MOBID-2 Pain Scale into different languages was required. In the present study, the participating caregivers' awareness, competence and interest seemed to increase noticeably, underlining the need for implementation of research results in NHs. Assessing the presence, intensity, etiology and medication of pain in Norwegian NH patients, as well as the education of the caregivers will be a natural consequence of this thesis.

To obtain more knowledge about the relationship between pain and behavioural disturbances in dementia, research will be undertaken to systematically follow elderly persons with dementia at home and in the NH. Efforts should be made to assess whether pain management and physiotherapy can improve behavioural disturbances in these patients.

Our study provided evidence that patients with severe dementia do not experience less pain intensity or fewer pain diagnoses and pain locations than patients in other stages of dementia. On the contrary, patients with severe dementia and ADVaD risk suffering more pain than other groups of demented and cognitively intact people. At this stage of the research, it seems natural to explore the underlying brain correlates of pain in patients with AD, with and without chronic pain as measured by fMRI. In addition, questions arise about whether the genetic contributions to pain are also apparent in patients with dementia.

Most of all, research into patients with dementia has to be supported in order to increase the focus on and interest in these weak patients, their relatives and caregivers. Our findings suggest that NH patients demonstrate a complex picture of suffering due to multi-morbidity and lack of communicative ability. The implementation of our research results has to be guaranteed in NHs, at home and in hospitals. Then, research will contribute to greater competence, reflection and development processes. For the sake of patients with dementia, their relatives and the staff, we hope that this thesis will help to create a basis for more dignity and an improvement in the quality of care in the NH, as well supporting research in Primary Health Care.

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APPENDIX I

UNIVERSITETET I BERGEN
Institutt for samfunnsmedisinske fag

Bettina.Husebo@isf.uib.no
Institutt for samfunnsmedisinske fag
Kalfarveien 31
5020 Bergen

Bergen, 09.07.2005

Til pasient/pårørende

Informasjon om deltakelse i en undersøkelse for å vurdere smerte hos eldre pasienter

Kjære .....

Du er pårørende/ verge av ..... født.....
som er pasient på Bergen Røde Kors Sykehjem.

Vi kontakter deg og pasienten fordi vi ønsker å gjennomføre en undersøkelse om smerte hos eldre pasienter med demens. Målet er å utvikle et enkelt vurderingsskjema for å fange opp smerteatferd hos disse pasientene.
Vi ønsker å inkludere..... i undersøkelsen.
Nedenfor gis en oversikt over hva undersøkelsen innebærer. Bruk deretter den tiden du trenger til å avgjøre om det er grunn til å anta at pasienten ikke ville være med i undersøkelsen. Diskutere vår forespørsel gjerne med pasient og familie.

Bakgrunn for undersøkelsen
Levealderen vil fortsette å øke og antallet demenspasienter blant de gamle tiltar. Litteraturen viser at eldre pasienter plages med smerte uansett oppholdssted: hjemme, på sykehjem eller sykehus. Situasjonen forverres når pasienten i tillegg har en demenssykdom eller kognitiv svikt, som 60-70% av sykehjemspasientene har. De er ofte ikke lenger i stand til å beskrive sine smerter. Kombinasjon av smerte og demens øker pasientens lidelse og forverrer andre lidelser. Til nå foreligger ingen gode undersøkelses- eller vurderingsinstrumenter på norsk for å vurdere smertetilstander og effekt av smertebehandling hos disse pasientene.

Formålet med undersøkelsen
Vår forskergruppe ønsker å utprøve et vurderingsinstrument av smerteatferd som kan bidra til å identifisere smerte hos pasienter med demens. Også behandling med smertemedisin er en del av undersøkelsen.

Undersøkelse og behandling
Prosjektet innebærer at pasienten vurderes av en geriatrisk sykepleier og ansvarlig lege etter anerkjente skjemaer og tester som man bruker under en geriatrisk vurdering. Vi ønsker også å registrere opplysninger om sykdommer og oppholdstid på sykehjem fra pasientens journal. I tillegg vil pleiepersonalet som kjenner pasienten best observere hun/han under stell, aktivitet og daglige gjøremål. Deretter fyller pleiepersonalet ut et enkelt smertevurderingsskjema. Dersom vi har mistanke om at en pasient plages av smerte skal han få individuell smertelindring med medikamenter etter Norsk legemiddelanbefalinger.

Videoopptak
Vi ønsker også å gjøre et videoopptak for å registrere typiske ansikts- og kroppsutrykk ved smerte. Videosekvenser skal brukes for å utprøve smertevurderingsinstrumentet. Videoen vil bli oppbevart forsvarlig nedlåst på Institutt for samfunnsmedisinske fag, Universitetet i Bergen. Studien avsluttes 4/2007, og videoen vil bli da sladdet.

Konfidensialitet
Opplysninger behandles konfidensielt og kun informasjoner som er nødvendige for studien vil bli innhentet. Dataene anonymiseres ved prosjekt slutt innen 4/2007 og vil bli forsvarlig oppbevart. Viktige opplysninger i forhold til smertebehandling vil bli lagt i pasientens journal. Hvis resultatene av studien blir offentliggjort, vil pasientens identitet ikke kunne gjenkjennes. Alt personell med tilknytning til studien har taushetsplikt. Prosjektet er meldt og godkjent fra De regionale komitéer for medisinsk forskningsetikk (REK Vest nr: 190.04), datatilsynet (Nr.: 2004/1656-2) og Helse- og omsorgsdepartementet (200502098./ASD).

Ansvarlige
Studien vil bli gjennomført av undertegnede. Ansvarlige veiledere er prof. dr. philos. Anne Elisabeth Ljunggren, dr. philos. Liv Inger Strand, begge ved Institutt for samfunnsmedisinske fag, Seksjon for fysioterapivitenskap, Universitetet i Bergen.
Det er helt frivillig å delta i studien, og pasienten kan trekke seg tilbake uten å oppgi noen grunn. Dette vil ikke ha noen innvirkning på hans/hennes nåværende eller fremtidige oppfølging og behandling på sykehjemmet.
Når du signerer vedlagte samtykke skjema, bekrefter du at du har mottatt dette informasjonsbrevet og at det ikke foreligger grunn til å anta at pasienten ville ha motsatt seg undersøkelsen.
Dersom du har spørsmål eller kommentarer, er du velkommen til å ta kontakt med meg (55586735 eller 48094660). Jeg er veldig glad om du sender tilbake ditt informasjonsskjema i vedlagt frankert svarkonvolutt.

Vennlig hilsen

Bettina S. Husebø
Avdelingsoverlege/ Forskningsstipendiat, Universitetet Bergen
Institutt for samfunnsmedisinske fag, Seksjon for fysioterapivitenskap

INFORMASJONSSKJEMA, VIDEO

Det foreligger ingen holdepunkter for at pasienten ..... ikke ville ha deltatt i den validitetsstudien for å undersøke et evalueringsinstrument for smerte hos eldre pasienter med demens.
Jeg er klar over at forskerteamet ønsker å registrere opplysninger om sykdommer og oppholdstid på sykehjem fra pasientens journal. Opplysninger behandles konfidensiell og kun informasjoner som er nødvendige for studien vil bli innhentet. Jeg er informert om at pasienten filmes under observasjonen. Videoen vil bli oppbevart forsvarlig nedlåst på Institutt for samfunnsmedisinske fag, Universitetet i Bergen. Studien avsluttes 4/2007, og videoen vil bli da sladdet.

Jeg er klar over at pasientens deltakelse er frivillig og at pasienten når som helst kan trekke seg tilbake uten ytterligere grunngiving, og at dette ikke vil få innvirkning på pasientens fremtidig oppfølging eller behandling ved sykehjemmet.

....
Signatur (pårørende) Dato

.....
Navn i blokkbokstaver

UNIVERSITETET I BERGEN
Institutt for samfunnsmedisinske fag
Seksjon for fysioterapivitenskap

Bettina.Husebo@isf.uib.no
Institutt for samfunnsmedisinske fag
Kalfarveien 31
5020 Bergen

Bergen 22.02.06

Til pleiepersonell

Informasjon om en undersøkelse for å vurdere smerte hos eldre pasienter

Kjære medarbeider,

Vi kontakter deg fordi vi ønsker å gjennomføre en undersøkelse om smerte hos eldre pasienter med og uten demens på Bergen Røde Kors Sykehjem. Målet med undersøkelsen er å utvikle et enkelt vurderingsskjema for å fange opp smerteadferd hos disse pasientene. Vi ber deg som pleieperson å hjelpe oss med testing av et smertevurderingsinstrument. Nedenfor gis en oversikt over hva undersøkelsen innebærer.

Bakgrunn for undersøkelsen
Levealderen vil fortsette til å øke og antallet demenspasienter blant de gamle tiltar. Litteraturen viser at pasienter over 70 år plages med smerte uansett oppholdssted: hjemme, på sykehjem eller sykehus. Situasjonen forverres når pasienten i tillegg har en demenssykdom eller kognitiv svikt, som 60-70 % av sykehjemspasientene har. De er ofte ikke lenger i stand til å beskrive sine smerter. Kombinasjon av smerte og demens øker pasientens lidelse og forverrer andre lidelser. Til nå finnes det ikke gode undersøkelses- eller vurderingsinstrumenter for å vurdere smertetilstander og effekt av smertebehandling hos disse pasientene.

Formålet med undersøkelsen
Vår forskergruppe ønsker å utprøve et vurderingsinstrument om smerteatferd som kan bidra til å identifisere smerte hos pasienter med demens.

Undersøkelse
Prosjektet innebærer at en geriatrisk sykepleier i samarbeid med avdelingens ansvarlig lege vurderer pasienten etter anerkjente skjemaer og tester som man bruker under vanlig smertevurdering. Vi ønsker også å registrere opplysninger om sykdommer og oppholdstid på sykehjem fra pasientens journal og gjennomfører en geriatrisk vurdering med anerkjente tester. I tillegg vil du som pleieperson som kjenner pasienten best, observerer pasienten under standardiserte aktiviteter. Deretter fyller du ut et enkelt vurderingsskjema for smerteatferd som heter MOBID-2 og ble utviklet av vår forskergruppe.
Det ble innhentet dispensasjon fra Helsedepartementet slik at taushetsplikten ikke er til hinder for at personalet fyller ut evalueringsinstrumentet.

Konfidensialitet
Opplysninger behandles konfidensiell og kun informasjoner som er nødvendige for studien vil bli innhentet. Dataene anonymiseres ved prosjekt slutt innen 4/2007 og vil bli forsvarlig oppbevart. Alt personell med tilknytning til studien har taushetsplikt.

Prosjektet er meldt og godkjent av De regionale komiteer for medisinsk forskningsetikk (REK Vest nr: 190.04), datatilsynet (Nr.: 2004/1656-2) og Helse- og omsorgsdepartementet (200502098./ASD).

Samtykke kompetente pasienter har gitt tillatelse om å registrere opplysninger (diagnoser og oppholdstid på sykehjem) fra journalen sin og at personalet kan utfylle et vurderingsskjema for smerteadferd. I forhold til pasienter med alvorlig demens foreligger dispensasjon fra Helsedepartementet om å registrere opplysninger om diagnoser og oppholdstid på sykehjem fra pasientens journal og at de ansatte kan fylle ut et vurderingsskjema for smerteatferd (MOBID-2) for den enkelte pasient.

Ansvarlige
Studien vil bli gjennomført av undertegnede. Veiledere er prof. dr. philos. Anne Elisabeth Ljunggren, dr. philos. Liv Inger Strand, prof. dr. philos. Rolf Moe-Nilssen, alle ved Institutt for samfunnsmedisinske fag, Seksjon for fysioterapivitenskap, Universitetet i Bergen.

Dersom du har spørsmål eller kommentarer er du velkommen til å ta kontakt med meg på telefon (55586735 eller 48094660).

Vennlig hilsen

Bettina S. Husebø
Avdelingsoverlege/ Forskningsstipendiat, Universitetet i Bergen
Institutt for samfunnsmedisinske fag, Seksjon for fysioterapivitenskap

SAMTYKKE SKJEMA

Jeg gir med dette mitt samtykke til å delta i den validitetsstudien for å undersøke et evalueringsinstrument for smerte hos eldre pasienter på Bergen Røde Kors Sykehjem.

Opplysninger behandles konfidensiell og kun informasjoner som er nødvendige for studien vil bli innhentet.

Jeg er klar over at samtykket er frivillig og at jeg når som helst kan trekke samtykket tilbake uten ytterligere grunngiving.

....
Signatur (pleieperson) Dato

.....
Navn i blokkbokstaver

APPENDIX II

Pasientdata – NR: **Dato:**

Navn	
Alder	
Kjønn	1=males 2=females
Avdeling	
Opphold i mnd	
Sivilstand	1=single 2=married 3=widowed 4=separated
Utdanning	1=basic 2=high school

DEMENS	
I. Primær degenerativ (Alzheimer: tidlig/ sen; subcortical: Parkinson, Huntington, Lewy-body	1=primer
II. Vaskulær demens Subcortical: små-kar, Blandet: trombo-embolisk, infarkt	2=circulatory
III. Sekundær demens (Hydrocephalus, metabolisk, nutriell, infeksjon, tumor etc)	3=second
4=primar+circulatory 5=primar+second 6=circulatory+second	
CT	0=no 1=CT
MR	0=no 1=MR

Primary conditions	**Pain etiology**	**Pain localisation**
0=no	0=no	0=no
1=circulatory	1=arthritis	1=back
2=musculoskeletal	2=old fracture	2=knee
3=nervous system	3=new fracture	3=foot/ankle
4=respiratory	4=neuropathy	4=shoulder
5=endocrine	5=muscle spasm	5=neck
6=digestive	6=contracture	6=wrist
7=neoplastic	7=osteoporosis	7=headache
8=genitourinary	8=polimyalgica rheumatica	8=hip
9=stroke	9=cancer	9=abdomen
10=others	10=wound/gangrene	10=chest wall
	11=claudicatio intermittens	11=elbow
	12=urea/gikt	12=heart/angina
	13=infection	13=rectal/pelvis
	14=headache	14=face/jaw
	15=angina pectoris	15=mouth
	16=others	16=others

Cognitive Impairment and daily functioning/results	
MMSE	
CDR	
ADL	
Cornell	
ICD-10 kriterie for dementia	
DSM-IV kriterie	

Blood/urine	**analysed**
Hgb, SR, hvite, vit B12, folsyre, Na, K, Ca, kreatinin, ALAT, albumin, CRP, fri T4, TSH, glucose	
Urin-stix	

Pasientdata – NR:	**Dato:**

Medikamentbruk (fylles ut av lege)

Alle faste og midlertidige medikamenter/ikke smerte medikamenter (unntatt laksantia, vitaminer eller v/behov medikasjon)	Dose per døgn (mg)
1.	
2.	
3.	
4.	
5.	
6.	
7.	
8.	

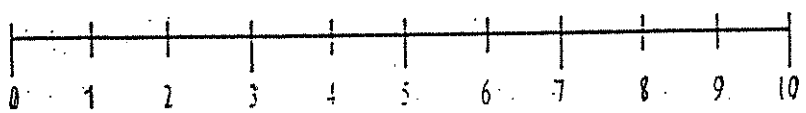
Alle faste og midlertidige medikamenter relatert til smertebehandling (unntatt laksantia eller v/behov medikasjon)	Dose per døgn (mg)
1.	
2.	
3.	
4.	
5.	
6.	

Grad av pasientens smerteintensitet vurdert etter legens undersøkelse

Nr:	
Pasientens navn:	
Post:	
Dato:	
Legenes navn:	

Kan pasienten gi valid selvrapport? (Sett kryss)	Ja ☐ Nei ☐ Usikker ☐
Har pasienten smerte? (Sett kryss)	Ja ☐ Nei ☐

Gi en helhetlig vurdering av pasientens smerte:



APPENDIX III

Mini mental status (MMS)

Norsk oversettelse ved Knut Engedal og Per Kristian Haugen.

Det er viktig å være klar over at en pasient godt kan skåre innenfor testens såkalte normalområde (24/30) og likevel ha en mental svikt/demenssykdom. Man bør legge stor vekt på opplysninger fra pårørende og være liberal med henvisning til spesialisthelsetjenesten dersom man er i tvil. Alder og utdannelse influerer på resultatet; jo yngre og høyere utdannelse, jo høyere skåre.

		Maksimal skåre	*Skåre*
1	Hvilket årstall har vi nå?	1	___
2	Hvilken årstid har vi nå?	1	___
3	Hvilken måned har vi nå?	1	___
4	Hvilken dag er det i dag?	1	___
5	Hvilken dato er det i dag?	1	___
6	Hvilket land er vi i nå?	1	___
7	I hvilket fylke/landsdel er vi nå?	1	___
8	I hvilken by/tettsted er vi nå?	1	___
9	Hva heter dette sykehuset/dette legekontoret hvor vi er nå?	1	___
10	I hvilken etasje befinner vi oss nå?	1	___
11	Fortell pasienten at du nå vil navngi tre gjenstander og at du ønsker at han skal gjenta disse navnene etter at du har sagt dem.	3	___
12A	Si "Trekk sju fra 100. Hvor mye har du da? Fortsett å trekke fra sju inntil jeg sier stopp" (For endelig skåre, se pkt. 12B) ___	5	
13	Spør pasienten om han kan huske navnene på de tre gjenstandene som han gjentok for litt siden.	3	___
12B	Dersom pasienten ikke oppnådde 5 poeng på oppgave 12A, be ham å stave ordet "SVERD" baklengs. Si. "Stav ordet "SVERD" forlengs – og nå stav det baklengs" ___	5	
	Bruk den høyeste poengsummen oppnådd enten på 12A eller 12B	5	___
14	Vis en blyant eller en penn. Spør pasienten hva denne heter (ikke hva den brukes til).	1	___
15	Vis et armbåndsur. Spør pasienten hva dette heter (ikke hva det brukes til).	1	___
16	Be pasienten gjenta følgende frase: "Aldri annet enn om og men."	1	___
17	Si følgende: "Hør nøye etter. Jeg ønsker at du skal gjøre følgende: Ta papiret med din høyre hånd, brett det sammen på midten en gang med begge hender, og legg det på gulvet/på stolen.	3	___
18	Be pasienten: "Les det som står skrevet på dette papiret inne i deg, og utfør det som står der".	1	___
19	Be pasienten: "Skriv en setning med mening på dette papiret."	1	___
20	Vis pasienten tegningen av de to femkantene. Be ham/henne om å kopiere femkantene på eget testark.	1	___

Se eget ark

Total skåre 30 ___

KDV

Klinisk demensvurdering

(CDR,Hughes et al 1982)
Norsk versjon ved Knut Engedal og Per Kristian Haugen.

Pasientens navn: _____ J.nr.: _____
Fødselsår/dato: _____ Dato utfylt: _____
Utfylt av: _____ Stilling: _____

Hukommelse	
Normal hukommelse, evt. lett vekslende glemsomhet	0
Lett hukommelsestap markert for nylig inntrufne hendelser. Hukommelsetapet virker inn på dagliglivets aktiviteter.	1
Moderat hukommelsetap. Viktige hendelser huskes, men nylig inntrufne hendelser glemmes helt.	2
Svært hukommelsetap. Bare fragmenter av tidligere hendelser kan huskes.	3
Orienteringsevne	
Orientert for tid og sted og egen person samt situasjon.	0
Vansker med tidsorientering, orientering for sted og egen person. Kan være geografisk uorientert.	1
Desorientert for tid og vanligvis også for sted.	2
Totalt desorientert for tid, sted, situasjon og egen person.	3
Vurderingsevne	
God vurderingsevne og klarer seg godt i dagliglivet.	0
Har vansker med å løse problemer av sammensatt natur. Sosial vurderingsevne er intakt.	1
Klart svekket evne til å løse problem. Sosial vurderingsevne er svekket.	2
Klarer ikke å løse problem. Sosial vurderingsevne er klart svekket.	3
Samfunnsaktiviteter	
Fungerer godt i arbeid, forening og selskapsliv. Kan ta vare på penger og gjøre adekvate innkjøp.	0
Trenger hjelp til å fungere i aktiviteter som nevnt. Kan imidlertid delta i slike aktiviteter og bevarer god fasade.	1
Kan ikke klare seg uten hjelp utenfor eget hjem, men er i stand til å bli tatt med på aktiviteter av andre.	2
Kan ikke klare seg uten hjelp utenfor eget hjem. Virker for syk til å fungere utenfor hjemmet.	3
Huslige gjøremål	
Fungerer godt i eget hjem, har hobbyer og/eller intellektuelle interesser.	0
Svak, men svekket interesse for huslige gjøremål, hobbyer og/eller intellektuelle sysler.	1
Helt enkle huslige sysler kan utføres. Hobbyer og/eller intellektuelle interesser er oppgitt.	2
Fungerer ikke i sitt eget hjemlige miljø.	3
Personlige gjøremål	
Steller seg selv.	0
Trenger av og til oppfordring til å stelle seg selv.	1
Trenger hjelp til personlig hygiene, påkledning. Kan ta vare på egne eiendeler.	2
Trenger mye hjelp til eget stell. Er ofte inkontinent.	3

Barthel ADL-index

(Mahony and Barthel,1965)
Til norsk ved Knut Laake

Pasientens navn: _____ J.nr.: _____
Fødselsår/dato: _____ Dato utfylt: _____
Utfylt av: _____ Stilling: _____

1. Kontinens for avføring

- ❑ 2 Kontinent siste uke.
- ❑ 1 Inkontinens ukentlig eller sjeldnere.
- ❑ 0 Større grad av inkontinens/trenger klyster for å være kontinent.

2. Kontinens for urin

- ❑ 2 Kontinent siste uke, mestrer bruk av kateter på egen hånd.
- ❑ 1 Inkontinens ikke oftere enn en gang daglig eller bruker kateter og trenger hjelp med dette.
- ❑ 0 Større grad av inkontinens.

3. Fødeinntak (maten plassert innen rekkevidde)

- ❑ 2 Kan skjære opp maten, ha på smør og pålegg uten hjelp, spiser innen rimelig tid.
- ❑ 1 Trenger noe hjelp med dette.
- ❑ 0 Må mates.

4. Personlig hygiene

- ❑ 1 Kan vaske ansikt, kjemme håret, barbere seg, pusse tenner (forutsatt at nødvendig utstyr er tilgjengelig).
- ❑ 0 Trenger hjelp/påminning til dette.

5. Påkledning

- ❑ 2 Kan kle seg på egen hånd, inklusive kneppe knapper og ordne glidelåser.
- ❑ 1 Trenger noe hjelp, men klarer mer enn halvparten.
- ❑ 0 Trenger mer hjelp.

6. Forflytning mellom seng og stol

- ❑ 3 Klarer seg uten hjelp.
- ❑ 2 Trenger litt hjelp/tilsyn, klarer seg fint med noe hjelp av en.
- ❑ 1 Trenger mye hjelp av en eller to personer, men kan sitte uten hjelp/tilsyn.
- ❑ 0 Kan ikke sitte, må løftes.

7. Hjelpebehov ved bruk av toalett/ dostol

- ❑ 2 Kan bruke toalett/dostol på egen hånd, mestrer av-/påkledning, tørker seg selv.
- ❑ 1 Trenger noe hjelp, men klarer mer enn halvparten.
- ❑ 0 Trenger mye hjelp.

8. Mobilitet innendørs

- ❑ 3 Kan gå alene, evt. med hjelpemidler, men ikke rullestol.
- ❑ 2 Trenger hjelp/tilsyn av en person, hjelp til å reise seg.
- ❑ 1 Uavhengig i rullestol (også vedr. snuing, passere dører o.l.).
- ❑ 0 Trenger mer hjelp enn dette.

9. Trappegang

- ❑ 2 Selvhjulpen opp og ned trapp, kan bære nødvendige hjelpemidler, (stokk, krykke).
- ❑ 1 Trenger hjelp, evt. til å bære hjelpe-middel.
- ❑ 0 Kan ikke.

10. Bading

- ❑ 1 Selvhjulpen ved bading/dusjing (evt. med hjelpemidler).
- ❑ 0 Trenger hjelp.

CORNELL

Skala for depresjon ved demens

(Alexopoulos et al. 1988)

Norsk versjon ved Dag Årsland

Pasientens navn:_____ J.nr.:_____

Fødselsår/dato:_____ Dato utfylt:_____

Utfylt av:_____ Stilling:_____

Skåringssystem

a Lar seg ikke evaluere.
0 Ikke til stede.
1 Moderat eller bare periodevis til stede.
2 Mye til stede.

Skåringen baseres på symptomer og tegn som har vært til stede siste uke før evaluering. Det skal ikke skåres hvis symptomene skyldes kroppslig funksjonshemming eller sykdom.

A:	**Stemningssymptomer**				
1	Angst, engstelig uttrykk, grubling, bekymring.	a	0	1	2
2	Tristhet, trist uttrykk, trist stemme, tar til tårene.	a	0	1	2
3	Manglende evne til å glede seg over hyggelige hendelser.	a	0	1	2
4	Irritabilitet, lett irritert, hissig.	a	0	1	2
B:	**Forstyrret atferd**				
5	Agitert, rastløs, vrir hendene, river seg i håret.	a	0	1	2
6	Retardasjon, langsomme bevegelser, langsom tale, reagerer sent.	a	0	1	2
7	Uttalt kroppslige plager (skår 0 hvis bare mage/tarm symptomer).	a	0	1	2
8	Tap av interesse, mindre opptatt av vanlige aktiviteter (skår bare hvis forandringen har skjedd raskt, dvs i løpet av en måned).	a	0	1	2
C:	**Kroppslige tegn**				
9	Redusert appetitt, spiser mindre enn ellers.	a	0	1	2
10	Vekttap (skår 2 hvis større enn 2 kg i løpet av en måned).	a	0	1	2
11	Tap av energi, blir fort trett, klarer ikke å holde ut aktiviteter (skåres bare hvis forandringen har oppstått raskt, dvs. i løpet av en måned).	a	0	1	2
D:	**Døgnvariasjoner**				
12	Døgnvariasjoner i humøret, humøret værst om morgenen.	a	0	1	2
13	Innsovningsvansker, sovner senere enn det som er vanlig for pasienten.	a	0	1	2
14	Hyppige oppvåkninger i løpet av natten.	a	0	1	2
15	Tidlig morgen-oppvåkning, tidligere enn vanlig for denne pasienten.	a	0	1	2
E:	**Tankeforstyrrelser**				
16	Selvmord, føler livet ikke er verdt å leve, har selvmordstanker, gjør selvmordsforsøk.	a	0	1	2
17	Dårlig selvbilde, selvbebreidelser, selvnedvurdering, skyldfølelse.	a	0	1	2
18	Pessimisme, ser svart på framtiden.	a	0	1	2
19	Stemningskongruente vrangforestillinger, forestillinger om fattigdom, sykdom eller tap.	a	0	1	2