A Closer Look at Pain in Nursing Home Residents

Een betere kijk op pijn bij verpleeghuisbewoners

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A CLOSER LOOK AT PAIN IN NURSING HOME RESIDENTS

Een betere kijk op pijn bij verpleeghuisbewoners

Proefschrift

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For all the happiness mankind can gain
Is not in pleasure, but in rest from pain

John Dryden (1631-1700)

CONTENTS

PROLOGUE

The impact of pain on the lives of people was already mentioned by the philosopher Saint Augustine, who lived from 354 to 430, saying 'The greatest evil is physical pain'.

In 1994, the Dutch Ministry of Health, Welfare and Sport designated pain expertise centers in four academic hospitals, acknowledging pain as a large problem in our society. The overall aim of the cooperating centers was to develop evidence based protocols for diagnostic measures and treatment, to accomplish patient-related research, and to expand knowledge about pain.

One of the major factors contributing to the undertreatment of pain is inadequate pain assessment. Although there is evidence suggesting that many older adults are able to report pain themselves using a pain intensity scale, there is a considerable cognitively impaired population for whom this is impossible. The Pain Expertise Center Rotterdam was given the task to study pain (behavior) in neonates and children with a cognitive impairment, later extended to elderly with a cognitive impairment. Both nationally and internationally the latter topic is of growing importance in our greying society, and media services regularly bring headlines such as: 'Many elderly people living with chronic pain in nursing homes are suffering needlessly', and 'Patients with dementia sometimes suffer more than necessary, because they are not able to communicate'.

This thesis comprises studies instigated by a study about prevalence of pain in nursing homes, showing an alarmingly high percentage of 68%.

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Introduction

INTRODUCTION

Aging

The worldwide number of elderly people is expanding significantly. By 2050, the proportion of people over the age of 65 in developed countries will have increased from 18% to 36%, and proportions of those older than 80 years will have increased threefold. This demographic phenomenon has been called 'double aging', i.e. there will be relatively more elderly people and they will reach increasingly older ages.

In the Netherlands, the number of persons older than 65 years is expected to grow from 2,3 million in 2007 to 3,9 million in 2050. At that time, about 24% of the Dutch population is older than 65 years compared to 14% in 2007. Of the senior generation, 35% will be 80 years and older.[1]

Next to higher life expectancy and a growth of the general population, the post-war 'baby boom' is largely responsible for this effect: this refers to the increase in birth rate beween 1946 and 1970. The first ones of this generation will reach the age of 65 in the year 2011. Figure 1 represents the numbers of people who are 65- and 80- years and older from 1950 and the prognosis up to 2050 in the Netherlands.

Meanwhile it has been recognized that the changing age structure of society has implications for retirement facilities, costs and demand on health care, and special care for elderly. A health-related issue like pain, however, has been neglected for a long time.

Pain in old age

Old age often comes with pain, which seems to be considered by many of this age group as normal at that period of life. Joint symptoms are one of the most prevalent causes of pain in an older population; in the Netherlands about 1,800,000 elderly are suffering from arthrosis.[2] Other important causes are rheumatoid arthritis, osteoporosis, cancer, diseases of the heart, vascular problems and peripheral neuropathies. Apart from pain, these conditions may bring limited mobility, decline in social life, depression, anxiety, sleep problems, etc. Then, general quality of life may diminish rapidly. Also age-associated psychosocial factors, such as loss of independency, loss of relatives or friends, may affect a persons' pain status.

In 2007 about 120,000 individuals in the Netherlands were living in nursing homes or residential homes.[3] Many international studies show high prevalences of pain in long-term care settings, even up to 80%.[4-8] Likewise, two Dutch studies in a residential and a nursing home show similar high pain prevalences, 69% and 68% respectively.[9,10]

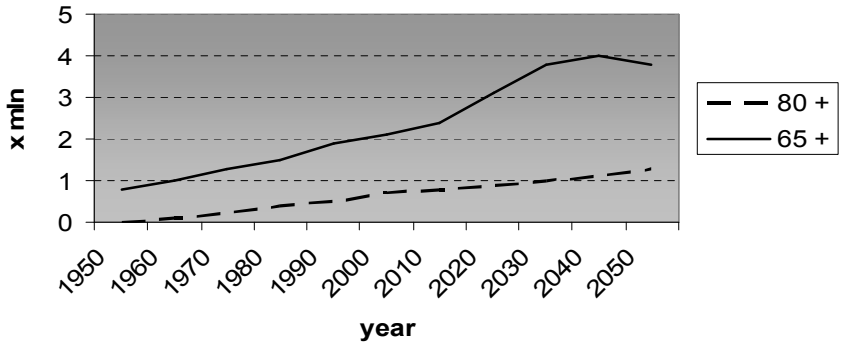

Figure 1 *Numbers of people who are 65- and 80- years and older from 1950 to 2050 in the Netherlands (Source: CBS population prognosis).*

Pain associations

The International Association for the Study of Pain (IASP), founded in 1973, launched 2006-2007 as the Global Year Against Pain, focusing on pain in older persons. IASP promotes the Global Year Against Pain to raise awareness of pain worldwide. In addition, members of the American Pain Society have created a Special Interest Group 'Pain in older persons' that focuses on the unique aspects of the basic science, diagnosis, and clinical aspects of pain in an older population. The aims of this group are to facilitate and disseminate research and best practice in the treatment of acute and chronic pain in the elderly and those with chronic illness. In 1975 the Dutch Association for the Study of Pain (Nederlandse Vereniging ter Bestudering van Pijn, NVBP) has been established as part of a division of the IASP. This multidisciplinary professional organization shares the same goals. Yearly, several national pain symposia about pain in elderly are organized for different disciplines working in the field.

Assessment and management of pain in older persons

Pain assessment and treatment in the elderly still leaves much to be desired.[4,11,12] Data on the presence of pain in cognitively impaired elderly are scarce, and studies on quality of treatment in these patients are lacking.

We do know that older people (> 85 years) and cognitively impaired individuals run an even greater risk of undertreatment of pain than younger persons without cognitive impairment.[13] The IASP defines pain as 'an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage'. Presently, another definition has been added and widely used, originally from pain expert Margo McCaffery. She described pain as 'whatever the experiencing person says it is, existing whenever the person says it does'. So, no matter the definition you prefer, pain is a feeling that hurts and is accompanied by physical and emotional aspects. From McCaffery's definition it would follow that self-report is the gold standard in measuring pain. Elderly persons, however, traditionally underreport their pain, because they assume pain is inextricably bound up with aging, or are convinced that 'good' persons should not

complain.[14,15] Furthermore, for fear of medication, i.e. drug side-effects and risk of addiction and tolerance, they will be reluctant to report pain. Moreover, slow or even absent reaction as a result of visual, hearing, speech or motor impairments will often make it more difficult to detect pain. Emotional and behavioral problems may have an impact as well.

On the other hand, caregivers might also have a hand in the ineffectiveness of pain treatment. Both physicians and nurse caregivers may lack knowledge about pain assessment, pain medication, possible side-effects, and changes in pharmacokinetics and -dynamics in older persons. Miscommunication between caregivers has been mentioned as another barrier for effective pain treatment.[16-19]

Conditions such as dementia, aphasia, delirium, and acquired brain injury may result in a person's inability to express pain. The assessment and management of pain in cognitively impaired and non-verbal persons is therefore an even greater challenge. Several studies showed that cognitively impaired patients are at higher risk for undertreatment.[20-22]

Pain system

The well-known pain model of Loeser describes pain in four simple circles, from nociception to perception, followed by experience, and eventually leads to behavior (Figure 2).[23] Pain behavior is the behavior, e.g. language, posture, limitations in activities, that the patient exhibits as a result of experiencing pain.

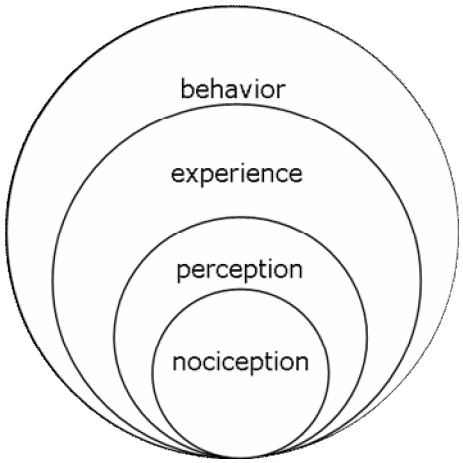

Figure 2 *Circle of Loeser*

The pain system can also be divided in the lateral and medial part. The medial pain system is connected to different pain aspects, such as motivational-affective ones, and the sensory-discriminative aspects can be linked to the lateral system. Based on this system several studies have been conducted in patients with different types of dementia compared to healthy controls. Dementia seems to affect these systems, which can lead to changing pain experiences. Moreover, differences in pain experience between the different types of dementia are present.[24-26] Scherder and colleagues tried to visualize this with the pain system of a healthy person as the starting point (Figure 3).[27] In 2005, Scherder and colleagues published a clinical review on recent developments in pain in dementia, underlining the importance of regular pain measurement, irrespective of cognitive status, and the need of more consistent distinction between the two pain systems and various types of dementia in both experimental and clinical studies.[28] Clearly, the pain system and neuropathology underly the different types of dementia. Therefore, combination of clinical and neuropathological research can contribute to a more widespread understanding.

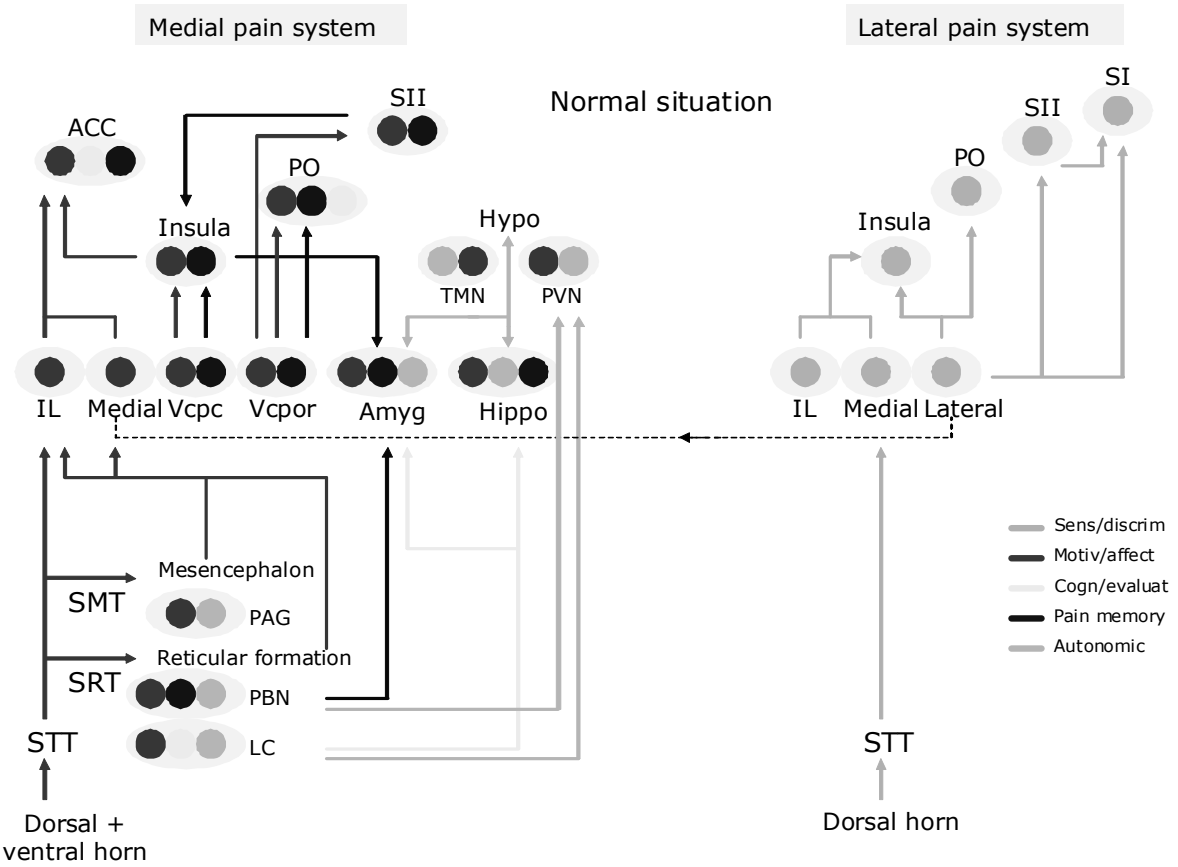

Figure 3 *Subcortical and cortical areas and pathways of the medial and lateral pain systems. Most of the brain areas contribute to more than one pain pathway.*
PO = parietal operculum; TMN = tuberomamillary nucleus; PVN = paraventricluar nucleus; ILN = intralaminar thalamic nuclei; MTN=medial thalamic nuclei; SMT = spinomesencephalic tract; PAG = periaqueductal grey; SRT = spinoreticular tract; PBN = parabrachial nucleus; STT = spinothalamic tract; LC = locus coeruleus

The use of a pain observation scale in practice

When pain can not be verbally reported, we could turn to observing 'behavior'. Scales have been developed to this aim. Provided they are reliable and valid, they may yield important information for (more) appropriate pain management. The use of behavioral instruments is especially advocated for those who are unable to report pain verbally. At the start of our research project in 2002, we identified six available scales designed to measure pain and/or discomfort in older persons. After a careful review, we judged these to have insufficient or limited psychometric properties or other negative 'characteristics', too complex, unsuitable for clinical practice, or focusing more on discomfort rather than pain.

Pain in comparable patient groups

Useful pain behavioral observation scales have been developed for other individuals who also can not reliably report pain, such as neonates, children less than 3 years of age and cognitively impaired children.[29,30] One example is the COMFORT-behavior scale, developed and validated to measure postoperative pain in neonates and young children.[31] Furthermore, both the Checklist Pain Behavior (CPG) and the Non-Communicating Children's Pain Checklist (NCCPC) have been found reliable and valid to measure pain in children with a profound cognitive impairment.[32,33] The shared aspect between preverbal children and cognitively impaired or non-verbal individuals of all ages – namely inability to verbally report pain – triggered us to develop a new observation pain scale for cognitively impaired elderly.

SCOPE OF THIS THESIS

Our initial goal was to assess pain in an elderly nursing home population. During an explorative phase, however, we came to realize that nursing homes (in the Netherlands) also accomodate persons younger than 65 years. Therefore, we gave our research a broader perspective focusing on all nursing home residents who could not communicate their pain. Based on a literature review, we found the available pain observation scales for this target group insufficient.

The aims of this thesis are threefold:

1. To evaluate pain (management) in Dutch nursing homes;
2. To develop a reliable, valid and easy to use pain observation scale for those residents who are not able to report their pain themselves;
3. To implement the new scale in daily nursing practice.

CONTENT OF THIS THESIS

Chapter 2 describes the prevalence and intensity of pain in elderly living in (Dutch) nursing homes, the characteristics of pain and which analgesics are prescribed, and the impact of pain on daily functioning.

Chapter 3 explores the agreement between caregivers' and relatives' reports about nursing home residents' pain.

Chapter 4 reviews pain observation scales used in or developed for older adults with (severe) cognitive impairments and/or communication difficulties.

Chapter 5 presents the results of our pilot phase, and the first draft of a new scale to assess pain in older adults with communication difficulties.

The objective of **chapter 6** is to identify and estimate the dimensional structure, reliability and validity of the Rotterdam Elderly Pain Observation Scale (REPOS).

In **chapter 7** the relation between cognitive level and resident's pain behavior and pain treatment is examined.

Chapter 8 describes the preliminary findings of the implementation process of the REPOS in one nursing home.

Chapter 9 addresses the main findings and conclusions of this thesis, and provides implications for future research.

Finally, both an English and Dutch summary are presented.

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Pain management in Dutch nursing homes leaves much to be desired

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Submitted

ABSTRACT

The present cross-sectional multicenter study describes several aspects of pain, pain intensity and pain treatment in a Dutch nursing home population. A standardized pain questionnaire, including the Numeric Rating Scale (NRS), was used to measure aspects of pain and intensity for present pain, pain experienced previous week, and tolerable pain. The eligible sample comprised 320 residents (median age 79 years), of whom 233 residents completed the questionnaire. Sixty-six per cent (n = 153) experienced (mostly chronic) pain either in the previous week (median NRS 6) or at present (median NRS 5). Intolerable pain was reported by 41% of the residents. The higher the pain scores, the more interference with activities of daily living (ADL) was reported. Of the 153 residents with pain, about a quarter did not receive any pain medication, sixty-five (43%) received step 1, 13 (9%) step 2, and 16 (11%) step 3 analgesics. Most residents (60%) were satisfied with pain treatment, whereas 21% was not. Considering the high prevalences, and intensities of pain, pain management in Dutch nursing homes leaves much to be desired. Apparently, residents do not seem to expect effective pain management. Awareness and knowledge about pain assessment and treatment, however, needs to be improved and implemented in daily practice.

INTRODUCTION

Studies conducted over the last two decades have reported similarly high prevalences of pain in older adults in different countries.[1-6] Pain may well reduce quality of life, seeing that it can lead to depression, anxiety, sleep disruption, or limitations in daily functioning and cognitive impairment.[4,7-9] Effective pain management, therefore could diminish these burdens substantially.[10,11] It is against this background that the International Association for the Study of Pain (IASP) launched the Global Year Against Pain in Older Persons in 2006. Its goal was to achieve more research efforts spent on ways to measure and treat pain in older adults, so as to improve pain management, and indirectly quality of life in this growing vulnerable group.

Of the several ways to measure pain in older adults, self-report is seen as the gold standard. In a Dutch nursing home population, two studies using the Nottingham Health Profile for self-reported pain found that 47 to 68% of residents reported any pain.[5,12] Another self-report instrument is the numerical rating scale (NRS), which has been validated in older adults and in comparison to other pain scales showed to be best feasible, with good convergent validity and test-retest reliability.[13,14]

The present explorative multicenter study describes several aspects of pain, pain intensity and pain treatment in a Dutch nursing home population by setting out to answer the following questions:

1. What is the prevalence and intensity of pain in older adults living in Dutch nursing homes?
2. What are the characteristics of pain and which analgesics are prescribed?
3. What is the impact of pain on daily functioning?

METHODS

Design

The study had a multicenter cross-sectional design, and was embedded in an implementation project of daily pain registration. A pain questionnaire, including a numerical rating scale (NRS), was used to describe the prevalence, intensity and several aspects of pain. Although the study was performed within the framework of localized care improvement efforts, for which ethical clearance was not necessary, the boards of directors of all nursing homes involved approved the study.

Participants

The present study was conducted between 2001 - 2005 in four nursing homes, i.e. in nine somatic wards (2 - 3 per home) and two rehabilitation wards. All residents of these 11 wards were eligible, except if cognitive impairment had been diagnosed

before or was assumed to be present based on the medical diagnosis or the caregivers' opinion. The nursing home residents had the right to refuse participation.

Measures

A standardized pain questionnaire based on the valid McGill Pain questionnaire-Dutch Language Version (MPQ-DLV)[15,16] was used to determine several aspects of pain (Table 1). Pain intensity was assessed by means of the NRS, which ranges from 0 (no pain) to 10 (worst possible pain). Residents themselves rated intensity of present pain, pain previous week and tolerable pain. Score of 0 indicates no pain, 1 to 4 mild pain, 5 and 6 moderate and 7 or higher severe pain. Intolerable pain is present if the reported tolerable pain scores are lower than the scores of present pain intensity and pain intensity in the previous week.[17] Chronic pain was defined as pain lasting at least three months. To study the impact of pain on daily functioning in the previous week, residents rated on a 4-point Likert scale (none, fairly, somewhat and much) the extent to which pain had interfered with sleep, activities of daily living (ADL), and other daily activities. Likewise, they rated effects on tension, depression and anxiety in the previous week. Furthermore, we asked the residents to pronounce upon five statements, based on the valid Pain Attitude Questionnaire.[18] Response categories were: 'agree', 'disagree' and 'not agree/not disagree'.

The Karnofsky index was completed to assess residents' performance status. Scores range from 0, representing deceased, to 100, representing normal situation without complaints or diseases.[19]

We classified residents' most painful diagnoses by the WHO International Classification of Diseases (ICD-10, 1994). For example, post-stroke pain was classified under 'diseases of the circulatory system', severe decubitus under 'diseases of the skin and subcutaneous tissue' and pain caused primarily by arthritis under 'diseases of the musculoskeletal system and connective tissue'.

Analgesics were grouped into the steps of the World Health Organization (WHO) analgesic ladder. Step 1 consists of non-opioids (acetaminophen and NSAIDs), step 2 of weak opioids (e.g. codeine) and step 3 of strong opioids (e.g. morphine).[20] Co-analgesics (adjuvants) were classified into four categories, namely anti-depressants, anti-epileptics, corticosteroids and a fourth group of anxiolytics and hypnosedatives, mostly benzodiazepines. Use of co-analgesics were collected up to a maximum of 2 per resident.

Procedure

The researcher administered the pain questionnaire to all eligible residents in several days per home. If the resident reported not to have pain at present, nor in the previous week, and did not receive analgesics, the questionnaire was

discontinued. On the day that the questionnaire was administered, the caregiving nurse completed the Karnofsky index for the resident in question and demographic and medical data were extracted from medical charts.

Statistical analyses

Data analysis was conducted with SPSS 14.0. For not normally distributed variables, median and inter quartile ranges (IQR) were used. Differences in demographics between the four nursing homes were analyzed by Chi-square test and Kruskal-Wallis test. The multiple linear regression method was used to identify interferences with sleep, ADL and other activities with pain intensity for previous week as dependent variable. For this analysis, the answer categories were recoded into 'no interference' (= 0) and 'a little to much interference' (= 1). As measures R-square and *P*-value were used.

All statistical testing took place at 0.05 level of significance (two-tailed).

Table 1 Content pain questionnaire with answer categories (n = 153)

Questions	**Answer categories**
Previous week pain?	yes or no
At this moment pain?	yes or no
No pain, but receives pain medication	yes or no
Location pain?	Body location
Pain same place(s)?	yes or no
Since when pain?	days / weeks / months / years
The onset of pain?	slowly / suddenly / don't know
Pain changed?	yes / no / don't know
Course of pain?	always the same; seizures and sometimes no pain; changing, but never gone
Pain number at this moment	0 - 10
Pain number previous week	0 - 10
Pain number tolerable	0 - 10
Pain interference with sleep in previous week?	no / a little / reasonable / much
Pain interference with ADL in previous week?	"
Pain interference with other activities in previous week?	"
Did you feel tense in previous week?	"
Did you feel depressed in previous week?	"
Did you feel anxious in previous week?	"
Pain is part of aging	Agree / not agree, not disagree / disagree
If I am in pain I always report that	"
Nurses have enough attention for my pain complaints	"
Physician has enough attention for my pain complaints	"
I am satisfied about pain treatment	"

RESULTS

Characteristics study population

A total of 320 residents were eligible, respectively per home 78, 30, 88 and 124 (Table 2). Their median age was 79 years (IQR 73 to 84) and 70% were females. The median stay in the nursing home was 13 months (IQR 3 to 33). The median Karnofsky-score was 50 (IQR 40 to 60). Most residents (n = 131) were diagnosed with a disease of the circulatory system, followed by musculoskeletal diseases and connective tissue (n = 99), and diseases of nervous system (n = 44). Comorbidities were present in 226 (71%) residents. Diseases of the circulatory system (n = 87) and endocrine, nutritional and metabolic diseases (n = 63) were most prevalent comorbidities, followed by diseases of the musculoskeletal system and connective tissue (n = 48), mental and behavioral disorders (n = 38) and diseases of the nervous system (n = 28). Significant differences in demographics were found between the four homes for gender (P = 0.01), duration of stay (P = 0.03), and Karnofsky-score (P = 0.00) (Table 2).

Characteristics of pain and pain treatment

For 87 of the 320 residents (27%) the pain questionnaire could not be (fully) completed for various reasons (Figure 1). Of the remaining 233 residents, 153 (66%) answered positive on the question whether they were in pain, experienced either in the previous week or at present. For most of them (72%) the pain was chronic, and had developed either gradually (63%) or suddenly (36%). Pain was described as: periodic (43%), constant but with varying intensity (37%), and of constant presence and intensity (16%). Most reported pain locations were legs (39%), followed by shoulder and arms (19%).

Table 2 Resident's characteristics per home

	NH1 n = 78	**NH2 n = 30**	**NH3 n = 88**	**NH4 n = 124**	***P*[1]**
Gender female N (%)	56 (72)	25 (83)	68 (77)	74 (60)	0.01
Median age in years (IQR)	79.5 (72.5 to 84.0)	80.5 (73.8 to 88.0)	81.0 (75.0 to 84.0)	78.0 (71.0 to 84.0)	0.42
Median stay in months (IQR)	14.5 (6.0 to 31.3)	7.5 (2.0 to 24.8)	7.5 (3.0 to 20.8)	16.5 (3.0 to 43.0)	0.03
Median Karnofsky (IQR)	40.0 (40.0 to 50.0)	50.0 (50.0 to 60.0)	40.0 (40.0 to 50.0)	50.0 (40.0 to 70.0)	0.00

[1] *two-tailed*

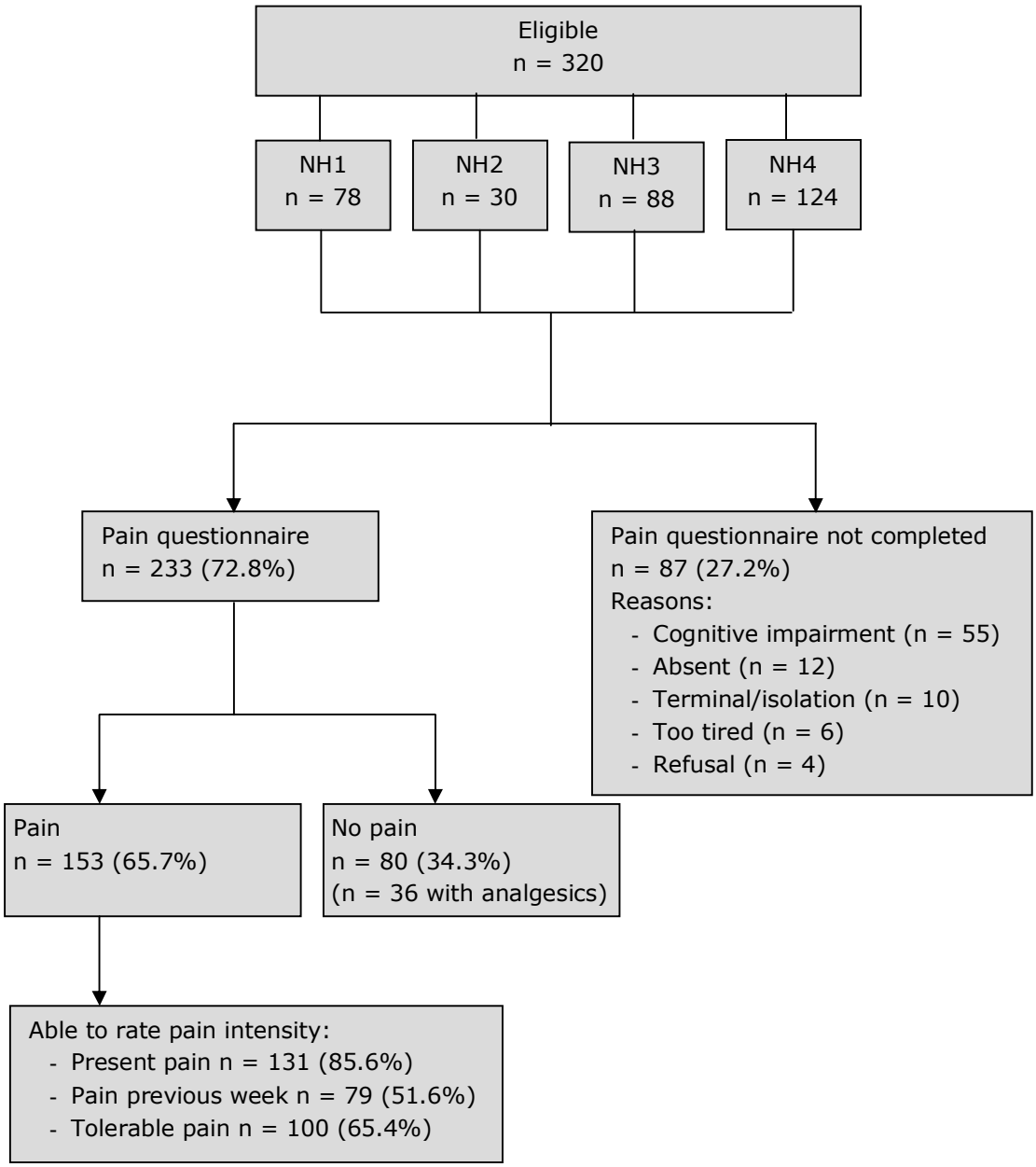

Figure 1 *Flow diagram study population*

Most residents reported moderate or severe pain (Table 3). Median pain intensity for present pain of 131 residents was 5 (IQR 2 to 7), and for 79 residents who rated their pain intensity for previous week, median was 6 (IQR 4 to 7). Eighty-eight residents reported a NRS ≥ 4 at present, and intolerable present pain was reported by 41% of the 100 residents who were able to rate their tolerable pain intensity.

Table 3 Reported present pain and pain previous week according to the residents

Pain	**No pain n (%)**	**Mild pain n (%)**	**Moderate pain n (%)**	**Severe pain n (%)**
Present n = 131	28 (21.4)	29 (22.1)	36 (27.5)	38 (29.0)
Previous week n = 79	2 (2.5)	18 (22.8)	27 (34.2)	32 (40.5)

Table 4 presents the highest prescribed analgesics according to the WHO ladder for total group (n = 320), further differentiated for those who completed the pain questionnaire (n = 233). Of the latter group, 112 residents (48%) received regular analgesics, 39 (17%) received only as needed analgesics, and 82 (35%) did not receive analgesics at all. The majority of the residents in pain (61%) received analgesics on routine basis and 38 (25%) did not receive analgesics at all. Of the 88 residents with a NRS ≥ 4 for present pain, and the 41 residents with intolerable pain at present, respectively 19 (22%) and 12 (29%) residents did not receive any pain medication. About half of the total 320 residents, and the 153 residents with pain, received at least one co-analgesic drug. Benzodiazepines were the most frequently prescribed co-analgesics, followed by antidepressants.

Table 4 Highest prescribed analgesics according to WHO ladder for total group (n = 320) and group who completed the pain questionnaire (n = 233)

	Total group (n = 320)	**Completed questionnaires (n = 233)**	
	n (%)	Pain (n = 153) n (%)	No pain (n = 80) n (%)
No prescribed analgesics	121 (37.8)	38 (24.8)	44 (55.0)
Prescribed analgesics			
Routine Step 1 (non-opioids)	109 (34.1)	65 (42.5)	17 (21.3)
Routine Step 2 (weak opioids)	14 (4.4)	13 (8.5)	1 (1.2)
Routine Step 3 (strong opioids)	23 (7.2)	16 (10.5)	-
As needed	53 (16.5)	21 (13.7)	18 (22.5)
Prescribed co-analgesics			
Benzodiazepines	145 (45.3)	73 (47.7)	33 (41.3)
Antidepressants	36 (11.3)	21 (13.7)	6 (7.5)
Anti-epileptics	24 (7.5)	12 (7.8)	4 (5.0)
Corticosteroids	9 (2.8)	7 (4.6)	1 (1.3)

Impact and perception of pain and pain treatment

Fifty-five per cent of the 153 residents in pain stated that pain interfered with sleep, ADL (61%), and other activities (53%). The multiple linear regression method was used to explore these influences on the level of pain intensity for previous week. Only one significant effect was found, i.e. the higher the pain scores, the more interference with ADL was reported (R-square = 0.11; *P* = 0.02). More than half of the residents (62%) felt a little to seriously tense, 59% was feeling depressed and 31% anxious.

Forty per cent of the responding residents agreed with the statement 'Pain is part of aging'. Only 40% indicated they always reported pain to the nurse. More than half of the residents agreed with the statement 'nurses have enough attention for my pain complaints' and 'the physician has enough attention for my pain complaints'. Sixty per cent was satisfied with pain treatment, and 19% did not agree nor disagree with this statement (Table 5).

We compared these responses between the four nursing homes involved. Proportions of residents who reported nurses and physicians paid enough attention to their pain complaints ranged from 37% to 81%. Except for NH4, most of residents agreed rather than disagreed with these statements. In NH4, 45% of the residents disagreed with the statement that physicians pay enough attention, compared to 37% who agreed. Proportions of residents who were not satisfied with their pain treatment ranged between 14% (NH1 and 2) to 33% (NH4).

Table 5 Statements about pain and pain treatment

	n[1]	Agree n (%)	Not agree n (%)	Neither n (%)
Pain is part of aging	145	58 (40.0)	78 (53.8)	9 (6.2)
If I am in pain I always report that to the nurse	146	58 (39.7)	69 (47.3)	19 (13.0)
Nurses have enough attention for my pain complaints	145	86 (59.3)	29 (20.0)	30 (20.7)
My physician has enough attention for my pain complaints	144	80 (55.6)	38 (26.4)	26 (18.1)
I am satisfied about pain treatment	146	88 (60.3)	31 (21.2)	27 (18.5)

[1] *Differences in sample size were attributable to some residents not answering the question*

DISCUSSION

In the present study, we demonstrated that pain seems to be a common health problem in the nursing homes involved. Despite the use of different methods of measuring pain, others have reached a similar conclusion for the Netherlands,[5, 12] as well as for other countries, e.g. the United States, Canada, United Kingdom, and Norway.[1,21-23] In our study, we used one of the most reliable and valid instrument in this population, namely the NRS,[13,14] and found that more than half of the residents reported 4 or higher using NRS. Scores of this magnitude are thought to indicate a

higher risk of functional limitations and the need of pain treatment.[24] Therefore, once more, our findings signal the large problem of pain in older adults. The validity of this cut-off score can be questioned, however, seeing the individual differences in the way pain is experienced. In our study, we therefore also assessed intolerable pain, and found that almost half of the participants who were able to rate their tolerable pain, rated their pain as intolerable. This proportion is much higher than that reported by Smalbrugge et al. (2007) in which about 15% of participants reported intolerable pain.[5] The discrepancy is probably inherent to the different ways of measuring and defining intolerable pain.

The reasonably low completion rates for pain intensity show that many residents find it difficult or are not able to report this. These findings are somewhat low compared to previous research, in which it was even found that most of moderately to severely impaired patients could report their pain using the NRS.[13,14] In addition, one of our exclusion criteria was having a cognitive impairment based on the medical diagnosis or by caregivers' opinion, and this would expect a high(er) completion rate. A limitation, however, was the lack of objectively measuring the cognitive level. Inadequate or unclear explanation about the NRS by the interviewers could be another reason of the low completion rates. Overall, memory decline as part of aging may be involved, because the completion rate for pain previous week was much lower (52%) than that for present pain (86%). It is well known that elderly people have short term memory problems, which makes it difficult to know for sure if the reported pain score is reliable, especially for pain previous week. In case of reasonable doubt someone not fully understand the method of NRS and the fact that older adults often not want to report their pain, the use of a pain observation scale can be very helpful. In order to chose a reliable and valid behavioral instrument, several pain observation scales were reviewed.[25,26]

The relationship between pain intensity and the use of analgesics deserves attention as well. In the current study, about a quarter of the residents who were in pain did not receive analgesics, which is in line with the findings of other studies.[11,27,28] Focusing only on those residents who reported high pain scores (NRS ≥ 4) or intolerable pain, similar percentages were found for the ones who did not receive any pain medication. Most of those who did receive analgesics were prescribed step 1. Obviously, in clinical practice, analgesics prescription is not accurately followed by the steps suggested by the WHO, resulting in less than effective pain management.
Undertreatment in older adults could be explained from different perspectives. First, physicians have been found to be reluctant to prescribe analgesics for fear of the higher risks of side effects and medication-interaction problems in older adults.[29,30] Second, pain in older adults is often chronic, and this is a type of pain that nurses tend to underestimate.[31,32] Third, as our study also shows, residents may be reluctant to report their pain, assuming that pain is irrevocably associated with aging.

Satisfaction about pain treatment, for that matter, was found to differ between the four nursing homes involved. An explanation could be the variation of educational background and the number of nursing personnel, assuming homes with more and higher educated nurses have more attention to and knowledge about pain, and therefore, more satisfied residents. In two of the four nursing homes, no more than half of the residents were satisfied, indicating the need to pay more attention to pain treatment in these homes. In the two homes in which satisfaction was highest more managerial involvement was present compared to the other homes, indicating that this can play a crucial role in this issue.

Several researchers have established relationships between pain, on the one hand, and emotional states, like depression and anxiety, and interference with daily activities on the other hand.[33-36] Large correlations between pain and depression,[37,38] and pain and anxiety were found.[3,5] In our study, we used just simple questions about emotions and interferences by self-report, which showed only interference with ADL was significantly related to higher pain scores. Consequently, a limitation of our study was the lack of an emotion specific instrument.

In conclusion, considering the high prevalences and intensities of pain found in this study, it would seem that effective pain management is not yet generally accepted in Dutch nursing homes. Nevertheless, residents do not seem to expect this. We believe, therefore, that launching a global decade against pain in older adults is required to achieve a fundamental change in pain management.

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3

Assessment of pain: can caregivers or relatives rate pain in nursing home residents?

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Submitted

ABSTRACT

Aim
To compare pain reports of nursing home residents to the pain scores as judged by caregivers and relatives.

Background
The assessment of pain is difficult in moderately and severely impaired nursing home residents. For residents who are unable to self-report pain intensity scores anymore, proxies (i.e. relatives of caregivers) might be employed as alternative sources of information. The utility of these proxies in assessing residents' pain is not clear however.

Design
A multicenter cross-sectional study.

Methods
Pain intensity was evaluated by means of a Numeric Rating Scale. In addition, proxies were asked how certain they were with their pain report.

Results
The cohort of 174 residents (median age 82 years) consisted of 124 cognitively impaired/non-verbal and 50 cognitively intact residents. In total 293 proxies estimated the pain intensity of the residents: 171 caregivers and 122 relatives. All three parties reported median pain intensity during the preceding week as 6.0. Data were consistent with low to moderate Intraclass correlation coefficients between residents and caregivers, residents and relatives, and caregivers and relatives. Residents themselves judged pain intensity at rest significantly higher than did proxies. Caregivers scored significantly higher pain intensities if residents were prescribed analgesics, and significantly lower pain intensities if they were more satisfied with the prescribed analgesics. Relatives reported significantly higher pain intensities in intact residents compared with impaired residents.

Conclusion
We concluded that proxy report on presence and intensity of pain is unreliable, especially in cognitively impaired persons. The use of a standardized pain observation scale could be helpful.

Relevance to clinical practice
To improve estimating pain intensity in nursing home residents, caregivers should consider the use of a pain observation scale, especially in severely cognitively impaired and non-communicative residents. Furthermore, they should pay more attention on pain at rest.

INTRODUCTION

Prevalences of pain in nursing home residents are high, and range from 40 - 80%.[1-6] Self-report is known as the gold standard for assessing pain in adults. Studies showed that self-report measures can be used in elderly people, even in the mildly or moderately cognitively impaired.[7-9] Self-report of pain becomes problematic in residents who are cognitively impaired, e.g. as a result of psychogeriatric disorder or communication disorder following stroke or traumatic brain injury.[10-12]

Assessment of pain in cognitively impaired residents may be possible with the use of observation scales. Implementation of these scales in nursing practice, however, has proven to be difficult. Proxy reports as alternative source of information for the assessment of pain in nursing home residents might be a feasible alternative. Previous studies showed poor agreement between older adults' own pain ratings and caregivers' reports.[2,13-17] Mentes et al. suggested that relatives could be more valuable proxies, because they are more familiar with a person's habits, behavior and preferences.[18] Weiner et al., however, found small correlations between relatives' ratings and chronic pain ratings by cognitively intact nursing home residents themselves.[13] Shega et al. found that pain prevalence reports by community-dwelling persons with dementia and their family caregivers were congruent in 59% dyads and in 47% as to the level of pain intensity.[19] Studies have shown that caregivers tend to underestimate patients' pain, while relatives tend to overestimate patients' pain. Yet, agreement rates between both proxies seem to improve with higher cognitive performance levels of the persons assessed.[13,15,20]

Studies comparing both caregivers' and relatives' reports with nursing home residents' pain are scarce, specifically for populations with various cognitive functional levels. We therefore conducted a study aimed at evaluating the utility of proxies (i.e., caregivers and relatives) for the assessment of pain in nursing home residents, and different aspects influencing proxy reports.

METHODS

Design

In a prospective, multicenter cross-sectional study, resident's self-report of pain was compared with proxy reports by caregivers and relatives. The study was approved by the Medical Ethical Review Board of Erasmus University Medical Center Rotterdam. In addition, directors and client boards of the nursing homes involved approved as well.

Participants

The present study was conducted between 2001 - 2005 in six nursing homes in the Netherlands. Residents were divided into two groups on the basis of cognitive level: cognitively intact to mildly impaired residents (intact) versus moderately to severely cognitively impaired residents as well as non-verbal residents (impaired). The first group was thought capable of reliable pain report. Eligible for participation were those residents judged to be in pain as evidenced by a numeric rating 4 or higher on a 0 to 10 scale, assigned by themselves and/or a staff nurse.

For each resident, both the caregiver who was nursing and caring for the resident and a relative, mostly the legal representative, were asked to report the resident's pain. Relatives who never, or seldom came to visit the resident, or those who had visited the resident more than two weeks ago were excluded for the study.

Measures

Demographic and medical data

Demographic and medical data were extracted from medical and nursing records. Residents' most painful diagnoses were classified by the WHO International Classification of Diseases (ICD-10, 1994). Pain medication was typified by the WHO analgesic ladder. Type of medication prescription (routinely or as needed) was collected.

Residents' cognitive status was established from the Mini Mental State Examination (MMSE). This is a valid and reliable instrument to assess cognitive status of older adults. Scores 0 to 9 indicate severe cognitive impairment, scores 10 – 17 moderate cognitive impairment, scores 18 – 23 mild cognitive impairment, and scores 24 to 30 no cognitive impairment.[21]

The Numeric Rating Scale (NRS), in which 0 represents no pain and 10 represents the worst imaginable pain, was used to rate intensity of pain experienced in the previous week and at rest. The NRS has been found reliable and valid for intact to even moderately cognitively impaired patients.[7,22] Residents' pain intensity was assessed by residents themselves if possible, caregivers, and relatives. In addition, caregivers and relatives indicated: (1) certainty of the reported pain intensity on a 5 point likert scale, varying from quite certain to quite uncertain; (2) whether they were satisfied with the pain treatment. Caregivers additionally stated working experience and the length they had known the resident. Relatives were asked how they were related to the residents and how often they visited.

Procedure

After informed consent was obtained, one of the two researchers (NB, RvH) visited a resident for a face-to-face interview. Demographic, medical information, including analgesics use, was collected, as well as cognitive status. The researcher

administered the interview to the caregiver on the same day as the resident. The relative in question was then interviewed by telephone within two weeks.

Statistical analyses

Findings were statistically analyzed with SPSS 14.0. Mean and standard deviations (sd) are presented for normally distributed variables and median and inter quartile ranges (IQR) for not normally distributed variables. Differences in demographics between the intact and impaired groups were analyzed by Chi-square test, Fisher's Exact test and Mann-Whitney U test.

Agreements between resident, caregiver and relative were established in several ways. Agreements on pain intensity scores were computed by means of Intraclass correlation (ICC) coefficients for continuous variables[23] on dyads only. ICC values below 0.40 were considered to reflect poor agreement, between 0.40 and 0.75 moderate to good, and above 0.75 indicate excellent agreement.[24] To further explore the degree of agreement between proxy-reports, we estimated the limits of agreement according to Bland and Altman.[25] The Wilcoxon Signed Rank test was applied to estimate the difference in pain scores between proxy reports.

Multiple linear regression analyses was performed with the level of pain intensity by proxies as dependent variable. Independent variables were cognitive level, routinely prescribed analgesics, satisfaction with prescribed analgesics, and certainty about pain intensity with gender and age of residents as covariates. For these analyses, nominal independent variables needed to be dichotomized into dummy variables. The five possible answers about certainty of pain ratings were dichotomized into two groups: 'not certain' to 'not certain/not uncertain' (0) versus 'quite certain' and 'fairly certain' (1). Prescribed analgesics on routine base was dichotomized into no (0) and yes (1), and satisfaction with prescribed analgesics into little to not satisfied (0) and fairly to quite satisfied (1). Variance Inflation Factors (VIF) were calculated to screen for multicollinearity.

RESULTS

Characteristics residents

Median age of the 174 residents (110 female/64 male) was 82 years (IQR 73 to 87), ranging between 26 and 97 years. The median nursing home stay was 16.5 months (IQR 5 to 38). The intact group included 50 residents with a mean MMSE score of 23.7 (sd 4.0); the impaired group included 124 residents, 53 of whom were capable of completing the MMSE with a mean score of 9.6 (sd 5.1). In both groups, musculoskeletal and circulatory problems most frequently gave rise to painful conditions. Significant differences in demographics between groups were found for age ($P < 0.05$), MMSE-score ($P < 0.001$), and length of stay ($P < 0.001$) (Table 1).

Nineteen impaired residents were able to complete the NRS for the previous week, and fifteen impaired residents for pain at rest.

Characteristics proxies

In total 171 caregivers were interviewed, 48 nurses caring for residents in the intact group and 123 for residents in the impaired group. Mean working experience was 16 years (sd 9), ranging between 1 and 40 years. About 30% had known the resident less than six months. In total, 122 relatives were interviewed, 28 in the intact and 94 in the impaired group. Eighty-four percent of the relatives were interviewed within a week after the resident had been interviewed. In the preceding month they had visited the residents a median of 12 times (IQR 5 to 30). Seventy-three (60%) were son or daughter, 26 (21%) partner, 5 (4%) father or mother, 10 (8%) brother or sister, and 8 (7%) were otherwise related. Fifty-two residents (30%) could not be matched with a relative for any of the following reasons: relatives never or seldom came to visit (n = 9), last visit had been more than 2 weeks ago (n = 4), no relatives at all (n = 2), and one eligible relative felt unable to collaborate because the resident had died meanwhile. Thirty-six (21%) relatives could not be reached within the study's two-week time frame.

Table 1 Sociodemographic and medical variables

	Intact n = 50	**Impaired n = 124**	***P*** [1]
Females n (%)	26 (52)	84 (68)	0.08
Median age in yrs (IQR)	78 (70 to 84)	83 (74 to 89)	0.02
Median length of stay in months (IQR)	9 (2 to 18)	24 (6 to 45)	0.00
Mean MMSE (sd)	23.7(4.0)	9.6 (5.1)	0.00
Completed MMSE n (%)	50 (100)	53 (44)	
Pain diagnoses n (%)			
musculoskeletal system	23 (46)	52 (42)	0.53
circulatory system	15 (30)	30 (24)	
skin and subcutaneous tissue	3 (6)	19 (15)	
nervous system	5 (10)	6 (5)	
injury, poisoning etc	2 (4)	7 (6)	
neoplasms	-	3 (2)	
digestive system	1 (2)	1 (1)	
genitals	-	2 (2)	
external causes	1 (2)	3 (2)	
unknown	-	1 (1)	

[1] *two-tailed.*
Abbreviations: IQR = Inter Quartile Range; MMSE = Mini Mental State Examination; sd = standard deviation

Table 2 Prevalences and intensities of pain

	Resident (intact group) n (%)	**Caregiver n (%)**	**Relative n (%)**
Pain during previous week *Yes* *No* *Do not know*	n = 50 50 (100) 0 0	n = 171 152 (88.9) 17 (9.9) 2 (1.2)	n = 122 82 (67.2) 27 (22.1) 13 (10.7)
Pain prevalence at rest *Yes* *No* *Do not know*	n = 50 15 (30.0) 33 (66.0) 2 (4.0)	n = 171 51 (29.8) 115 (67.3) 5 (2.9)	n = 122 42 (34.4) 65 (53.3) 15 (12.3)
Pain intensity previous week Median NRS (IQR)	n = 49 6.0 (5.0 - 7.0)	n = 168 6.0 (4.0 - 7.0)	n = 82 6.0 (4.0 - 7.3)
Pain intensity at rest Median NRS (IQR)	n = 48 4.0 (0 - 7.3)	n = 161 0 (0 - 2.0)	n = 87 0 (0 - 5.0)

Abbreviations: NRS = Numeric Rating Scale; IQR = Inter Quartile Range

Pain prevalence and intensity

Residents, caregivers, and relatives reported high pain prevalences for the previous week (respectively, 100%, 89%, and 67%), and similar median intensity scores (6.0). Prevalences for pain at rest were lower, especially reported by caregivers, respectively, 30%, 30%, and 34%. The intact residents themselves rated pain intensity at rest a median of 4.0, whereas both proxies rated this as 0. Relatives were more inclined to state 'do not know' than were caregivers (Table 2).

Poor to moderate intraclass correlation coefficients were found between caregivers and relatives on pain scores, for both groups of residents. The agreement between residents and caregivers was lower than that between residents and relatives, except for pain at rest in the impaired group. Agreements between caregivers and relatives show highest correlation coefficients for pain at rest in the intact group, and for pain during the previous week in the impaired group (Table 3).

Table 3 Intraclass correlation (ICC) coefficients between residents and proxies about pain intensity

	Residents-Caregivers		**Residents- Relatives**		**Caregivers-Relatives**	
	Pain in rest	Week pain	Pain in rest	Week pain	Pain in rest	Week pain
intact	0.25 n = 18	0.21 n = 21	0.48 n = 18	0.44 n = 21	0.23 n = 19	0.04 n = 22
impaired	0.19 n = 6	-0.12 n = 8	-0.51 n = 6	0.20 n = 8	0.03 n = 59	0.31 n = 54
Total	0.25 n = 24	0.15 n = 29	0.20 n = 24	0.35 n = 29	0.06 n = 78	0.26 n = 76

The mean difference score for pain intensity in the previous week was 0.01 (sd 3.2) (Figure 1) and at rest -0.88 (sd 3.8). Relatives tended to report higher pain levels for the at rest condition than did caregivers (*P* = 0.05).

From 107 to 164 caregivers, and 80 to 105 relatives responded to the question on certainty about the reported pain intensity. Eighty-three per cent of caregivers and 65% of relatives were certain about the intensity of pain in the previous week, and 83% of caregivers and 58% of relatives were certain about pain at rest. Pearson chi-square testing showed significant correlations between caregivers' degree of certainty about pain intensity in the previous week and their working experience (*P* = 0.01); and between caregivers' degree of certainty about pain intensity at rest and time having known the resident (*P* = 0.01). The relatives' degree of certainty about pain intensity was not significantly associated with either the number of visits in the past month or the type of kinship.

Multiple linear regression analysis revealed that caregivers scored significantly higher pain intensities if residents were prescribed analgesics (*P* = 0.001), and lower if they were more satisfied with the prescribed analgesics (*P* = 0.01) (R-square = 0.17). Relatives reported significantly higher pain intensities in intact residents than in impaired residents (*P* = 0.03). A trend was found for reporting higher pain intensity if residents were prescribed analgesics (*P* = 0.12, R-square = 0.14) (Table 4).

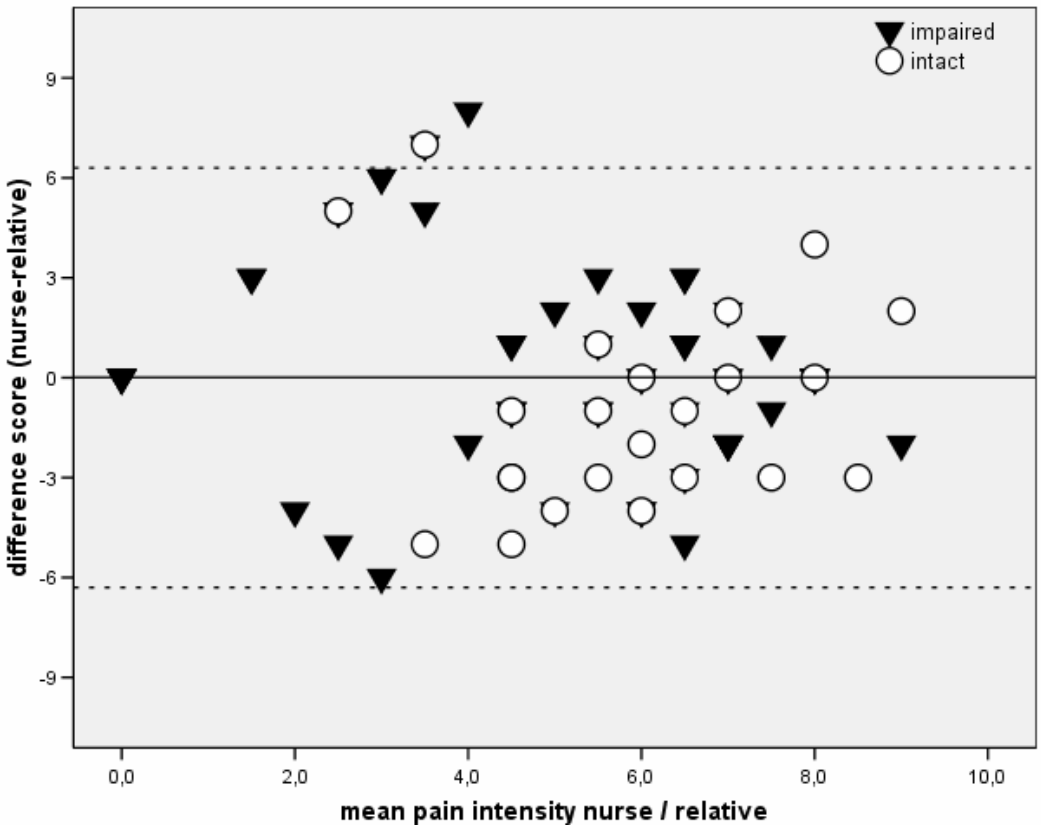

Figure 1 *Agreement between caregivers and relatives for pain in the previous week*

Table 4 Multiple regression analysis with proxy report of pain intensity in the previous week as dependent variable

Variable	Unstandardized B	95% CI for B	Standardized Beta	*P*
Caregivers (n = 159)				
Gender resident	-0.15	-0.84 to 0.55	-0.03	0.67
Age resident	0.02	-0.01 to 0.05	0.10	0.19
Cognitive level [1]	-0.26	-0.99 to 0.48	-0.05	0.48
Certainty about pain intensity [2]	0.67	-0.21 to 1.55	0.11	0.14
Use of analgesics [3]	1.43	0.74 to 2.11	0.31	0.00
Satisfied with analgesics [3]	-1.19	-2.01 to -0.37	-0.22	0.01
Relatives (n = 76)				
Gender resident	-0.50	-1.79 to 0.79	-0.09	0.44
Age resident	0.02	-0.04 to 0.07	0.08	0.52
Cognitive level [1]	1.54	0.15 to 2.93	0.26	0.03
Certainty about pain intensity [2]	-0.19	-1.66 to 1.29	-0.03	0.80
Use of analgesics [3]	1.02	-0.29 to 2.32	0.18	0.12
Satisfied with analgesics [3]	-0.82	-2.23 to 0.59	-0.13	0.25

[1] impaired group = 0/intact group = 1; [2] not certain = 0/certain=1; [3] no = 0/yes = 1
Abbreviations: CI= Confidence interval; MMSE = Mini Mental State Examination

DISCUSSION

The present study examined the utility of caregivers and relatives assessing pain in cognitively intact and impaired nursing home residents. Agreements between caregivers' and relatives' reports and possible explanations of the disagreements were evaluated.

Low to moderate agreement levels were found between residents and proxies for both pain at rest and in the previous week. Agreement levels between residents and relatives were higher than those between residents and caregivers. Both the assessment mode (pain at rest vs pain in previous week), and cognitive level of the residents seemed to influence the agreement levels. For pain at rest, disagreement between proxies was higher in cognitively impaired residents than in cognitively intact residents; the opposite held true for pain during the previous week.

Surprisingly, a majority of caregivers tended to be very certain and reported high pain scores, while at the same time the relative was also very certain and yet rated lower. It would follow that proxy ratings should be interpreted with caution, even if someone is very certain.

Median pain ratings of the proxies and the residents were similar. Still there is a statistical pitfall concerning the variability in pain ratings, as expressed by the low intraclass correlation coefficients. Also, further analysis, using the limits of agreement, reinforced the low agreements by the large variation. Though the medians of the proxy ratings are similar, relatives tended to report lower pain scores in the previous week than did caregivers, and for pain at rest this was the other way round.

Differences in pain assessment between caregivers and relatives might be ascribed to various factors. For one, 30% of caregivers had known the residents less than 6 months. Relatives obviously will have known the resident much longer, and may be expected to have better insight in a resident's common pain behaviors than caregivers. Also, residents might feel more confident to discuss pain problems with relatives. On the contrary, caregivers will have better insight in chronic pain exacerbations in daily care situations, such as washing, dressing, wound care and physical therapy. Relatives will not be aware of these often painful situations, and therefore might underestimate pain in the previous week. Caregivers, on the contrary, seem to rely more on verbal complaints of residents and may assume that residents who not complain and/or do not taking pain medication are free of pain. Research showed that relatives are more influenced by a person's aging process and therefore will overestimate pain sooner than caregivers do,[26] which is partly in congruence with our findings.

The few studies examining agreement between proxies and patients are largely in different patient populations, and did not assess pain specifically. Sneeuw et al. studied quality of life including pain intensity in cancer patients and found minimal differences between proxies and self-report of cancer patients.[27,28] In patients with dementia, Boyer et al. also demonstrated small differences in quality of life between both proxies and patients.[29] Novella et al. showed poor to moderate agreement in quality of life in Alzheimer's patients between patients and proxies.[30]

Remarkably, despite low agreement in pain estimation between residents and proxies, most of the caregivers and relatives were confident about their pain intensity ratings, 83% and 60%, respectively. The longer caregivers had known the resident, the more certain they were about pain intensity at rest. Analogously, the more working experience the more certain caregivers were about the reported pain intensity in the previous week.

Appearances may be deceiving therefore: caregivers with more working experience and longer acquaintance with a resident feel more certain about the pain assessment, but their estimation differs substantially from the resident's self-report. Another influencing factor is the resident's cognitive level, as demonstrated in previous work.[13,15,20] In the current study, relatives reported significantly higher pain intensities for cognitively intact residents than for cognitively impaired

residents. Surprisingly, cognitively impaired residents receive less analgesics than cognitively intact persons.[10,31] Both relatives and caregivers assigned higher pain ratings for residents who received analgesics on a routine basis. It seems that the mere fact of a resident receiving pain medication should lead proxies to believe the resident is in pain.

Good understanding and cooperation, not only between caregivers and relatives but also between relatives and residents, is essential to optimize quality of care. Miakowski et al. found significantly more mood disturbance and poorer quality of life in cancer patients who differed with their relatives about pain intensity than those dyads who did not differ.[32] Riley-Doucet found that caregivers developing pain management interventions for older cancer patients felt the need to include relatives.[33] Bogardus et al. demonstrated poor agreement between relatives and physicians about treatment goals in frail older adults.[34] As relatives cannot always reliably report patients' pain and symptom intensity, McMillan and Moody, therefore, suggest healthcare providers need to train relatives in conducting systematic assessments rather than assuming that relatives anyway will recognize pain symptoms.[35]

Limitations of this study

Dissimilar data collection could have influenced the results. Caregivers were interviewed face-to-face; relatives by telephone some time later. Nevertheless, considering the usually chronic character of the residents' pain, we feel this practice would have had minimum effect on outcomes.

Finally, as only few residents in the impaired group were able to report pain themselves, the agreement levels between these residents and proxies need to be interpreted cautiously.

Relevance to clinical practice

Overall, proxy ratings by nurses and relatives are not reliable, especially in cognitively impaired and non-verbal residents. Pain intensity can best be estimated by a pain observation scale in stead of a one-dimensional pain intensity scale, or at least a combination of both. Pain seems to differ not only on individual basis as well as in different daily situations. As pain at rest was rated higher by residents' than by nurses and relatives, this needs further attention.

Apparently, caregivers relate pain ratings to the prescribed analgesics. Yet, they should become more conscious of the effects of pain treatment. Moreover, treatment effects could be determined more easily using a pain observation scale.

CONCLUSION

From the findings of this study it can be concluded that proxy reporting on a one-dimensional pain intensity scale is of limited value, notably regarding cognitively impaired residents. Multidimensional pain observation scales show more potential for reliable and valid proxy pain assessment. We recommend caregivers and relatives should be taught to use and implement such observation scales.

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4

Observation scales for pain assessment in older adults with cognitive impairments and/or communication difficulties: a review

This chapter is based on the following publication:

Rhodee van Herk, Monique van Dijk, Frans PM Baar, Dick Tibboel, Rianne de Wit
Observation scales for pain assessment in older adults with cognitive impairments or communication difficulties.

Nurs Res 2007;56:34-43.

New data on the scales already reviewed in this article have been added, as well as details of recently developed scales.

ABSTRACT

Background
Several pain observation scales have been developed to accurately assess and manage pain in older adults with severe cognitive impairments and/or communication difficulties.

Objectives
To review relevant pain observation scales and their psychometric qualities.

Methods
We searched the literature for articles reporting the use of a pain observation scale in an empirical study, and describing psychometric properties in (older) adults with cognitive impairments and/or communication difficulties.

Results
Seventeen pain observation scales were included. Scales differed in numbers of items, types of categories, and psychometric properties. Facial expression, body movements, vocalization, and social behavior/mood are categories present in most of the scales. In terms of reliability and validity, however, most studies are too limited and/or incomplete to allow definite conclusions to be drawn about their usefulness in daily practice.

Discussion
As the available scales employ different methods of evaluating reliability and validity, and pursue different aims (e.g. type of pain), they cannot easily be compared. Nevertheless, a few are promising on the grounds of the preliminary validation results. We recommend these should be further examined on psychometric properties and their usefulness in different populations, because optimal pain assessment is necessary for efficient and effective pain treatment.

INTRODUCTION

Worldwide, the proportion of people aged over 60 years is growing faster than any other group: the WHO expects this group to grow by 223 percent between 1970 and 2025.[1] The consequences of aging are important for society in general, and for health care facilities and organizations in particular. A specific problem is pain, which is a serious and often unrecognized health problem among older adults. The reported prevalence of pain in the older adults varies, and may even reach 83% in nursing homes.[2]

National and international surveys show that pain is not always adequately assessed and managed. Pain being a subjective experience, self-report is usually considered the gold standard. Although tools such as numeric rating scales are appropriate for use in older adults with mild to moderate cognitive impairments, they may be of little help in persons with severe or advanced cognitive impairments.[3] Self-reports may be biased or impossible in persons who are cognitively impaired or have limited communicative skills. Therefore, these persons are at even higher risk for undertreatment of pain. Several studies reported that persons with communication difficulties were receiving less pain medication than did verbal persons.[4]

Thus, pain assessment in persons with severe cognitive impairments and/or communication difficulties should include observations of behavior. In 2002 the American Geriatric Society Panel on Persistent Pain in Older Persons published six common pain indicators: facial expressions, verbalizations/vocalizations, body movements, changes in interpersonal interactions, changes in activity patterns or routines, and mental status changes.[5] Closs et al. (2005) identified pain behavior in nursing home residents with different levels of cognitive impairment. They found three main groups of cues, namely verbal and body language cues, acute behavioral cues, and general changes in behavior or mood. Body movements were most frequently seen in persons with severe cognitive impairements.[6] Facial activity provides the most sensitive and specific nonverbal response during a painful event,[7] and facial activity can be a reliable parameter to assess pain in persons with communciation difficulties.[8,9]

This paper reviews the pain observation scales used in or developed for older adults with (severe) cognitive impairments and/or communication difficulties. Attention is paid to the different evaluation criteria and psychometric properties of these scales; furthermore we propose guidelines for the development of the ideal assessment scale.

METHODS

Literature search

Four computerized bibliographic databases (PubMed/Medline, PsycINFO, Cinahl and Picarta) were screened for publications from 1980 through 2007.

MeSH headings used were: pain (measurement) AND dementia OR Alzheimer OR (aged/aged, 80 and over/frail elderly) AND communication disorders. The reference lists of retrieved articles were also searched for additional references.

Articles were included if a pain observation scale was used in an empirical study, and psychometric properties were reported in (older) adults with severe cognitive impairments and/or communication difficulties, or if a scale had been specifically developed for use in older adults. Pain observation scales specifically developed for children and (critically ill) sedated hospitalized patients were excluded. Also, non-English articles were excluded, unless an English abstract was available.

Criteria

New instruments need to be tested for their psychometric properties before they can be used in practice. The instruments in this review were therefore assessed on relevant criteria, as described below.

Reliability

Interrater reliability is the agreement between two (or more) raters when both are rating the same subject(s). Intrarater reliability is the consistency of scores assigned by the same rater(s) at different times. Cohen's Kappa or intraclass correlation coefficients can be used to express degree of reliability. Kappa < 0.20 is considered poor, 0.21 - 0.40 fair, 0.41 - 0.60 moderate, 0.61 - 0.80 good, and 0.81 - 1.00 very good.[10,11] The higher the coefficient, the more reliable the agreement between raters.

Test-retest reliability is the extent to which a stable condition tends to produce similar scores over time. Because pain does not necessarily remain stable from one day to the next, test-retest stability coefficients have limited usefulness as estimates of the reliability of pain scales.[12] This outcome therefore is left out of consideration in the tables.

The basic assumption of internal consistency is that all items of a scale address the same theoretical construct. Thus, a scale is considered to be internally consistent when there is a high intercorrelation among the scores of the items. Cronbach's alpha coefficient (α) of 0.90 or higher indicates high internal consistency, but also redundancy among items. A coefficient of magnitude between 0.70 and 0.90 is adequate for group level comparisons. Scales with Cronbach's alpha lower than 0.70 are inadequate for most purposes.[13]

Validity

Generally seen as the most important metric property of a (pain) scale, validity is the degree to which a scale measures what it is supposed to measure.[14] Various types of validity are distinguished.

Face validity is the extent to which the test (or procedure) on first impression appears to measure what it is intended to measure.

Content validity is the extent to which the items of a scale are representative of some defined universe or domain of interest. Content validity is usually determined by expert judgment.[12] Overall, face and content validity have been well established for most pain scales and when proven satisfactory only indicate beginning validity. Therefore, these will be left out of consideration in this review.

Criterion validity assesses the relationship of a scale and a particular criterion. One aspect of criterion validity is predictive validity: the extent to which a scale is able to predict important outcomes.[12] Another aspect of criterion validity is concurrent validity, which refers to the comparability of a scale with a criterion. Because there is no gold standard for a nonverbal population, concurrent (or congruent) validity is usually determined by correlating a pain observation score with proxy reports or other existing pain observation scales.

Construct validity is the extent to which a scale assesses the specific domain or construct of interest. The most common sources of construct validity are the associations, often expressed by correlation coefficients, between scales of the same construct (i.e. pain) using different methods (convergent validity), or between scales of different constructs (i.e. pain and fear) or groups known to have a large amount of the construct (pain) versus those that do not, using the same method (discriminant validity). We used Cohen's criteria to judge the value of correlation coefficients: 0.10 to 0.29 (small r); 0.30 to 0.49 (medium r); and ≥ 0.50 (large r).[15]

Sensitivity to change or responsiveness of a scale has been mentioned as an aspect of validity. A sensitive or responsive pain scale should be able to detect changes, e.g. after administration of analgesics, and remain stable when no change has occurred.

Feasibility/clinical utility

The feasibility of a scale is its applicability in daily practice: Is it easy to use, and does it not take too long to complete it?

Clinical utility refers to the usefulness of the measure for decision-making. This may be established by calculating cut-off scores that discriminate between pain and no-pain. Cut-off scores enable pain assessment to be coupled with a treatment algorithm.

Table 1 Structural characteristics

Pain Observation Scale	Target population	Number of items	Categories[1]	Response category	Score range
Facial Activity Coding System (FACS)	Cognitively impaired (older) adults	46	1	Frequency and intensity	-
Pain Behavior Method (PBM)	Cognitively impaired (older) adults	5	1;2;4	Presence or absence	0 - 5
Discomfort Scale – Dementia of Alzheimer Type (DS-DAT)	Alzheimer patients	9	1;2;4;6	4-point scale	0 - 27
Doloplus-2	Nonverbal or cognitively impaired older adults	10	1;2;3;4;5	4-point scale	0 - 30
Behaviour Checklist	Cognitively impaired older adults	20	2;3;4;5;6	Presence or absence	-
Checklist of Nonverbal Pain Indicators (CNPI)	Cognitively impaired older adults	6	1;2;3;4	Presence or absence	0 - 6
Assessment for Discomfort in Dementia (ADD)	Patients with moderate to severe dementia	5	1;2;3;4;5;6	Presence or absence	-
Pain Assessment In Advanced Dementia (PAINAD)	Patients with (severe) dementia	5	1;2;3;4;6	3-point scale	0 - 10
Pain Assessment Tool in Confused Older Adults (PATCOA)	Confused older adults	9	1;2;4;6	Presence or absence	0 - 9
Pain Assessment for the Dementing Elderly (PADE)	Patients with dementia	24	1;2;3;4;5;6	4-point scale and multiple choice	24 - 96
Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)	Seniors with a limited ability to communicate	60	1;2;3;4;5;6	Presence or absence	0 - 60
PACSLAC-D (reduced PACSLAC, Dutch version)	Patients with dementia	24	1;2;3;4	Presence or absence	0 - 24
Non-Communicative Patient's Pain Assessment Instrument (NOPPAIN)	Non communicative patients	17	1;2;3;4;5	6-point scale	0 - 30
Abbey Pain Scale	Patients with end-stage dementia	6	1;2;3;4;5;6	4-point scale	0 - 18
Pain Assessment In Noncommunicative Elderly Persons (PAINE)	Non communicative nursing home residents	8	1;2;3;4;6	7-point scale	-
Elderly Pain Caring Assessment 2 (EPCA-2)	Non-verbally communicating older patients	8	1;2;3;4	5-point scale	0 - 32
Mobilization-Observation-Behaviour-Intensity-Dementia (MOBID)	Patients with severe cognitive impairment	3	1;2;3;6	Frequency and intensity	-

[1] *1: facial expression; 2: body movements; 3: social behavior/mood; 4: verbalizations/vocalizations; 5: eat/sleep pattern; 6: physiological indicators*

RESULTS

The literature search yielded seventeen pain observation scales that met the requirements for this study. Table 1 presents the structural characteristics, and Tables 2 and 3 the major psychometric properties.

Structural characteristics

One of the oldest observational scales, the *Facial Action Coding System (FACS)* enables to study different emotions, inlcuding pain.[16] The FACS employes explicit criteria to identify 46 discrete facial action units (AUs) involving specific muscles or groups of muscles, such as brow raise, brow lower, upper lip raise, lip stretch, mouth stretch, etc. Coders note frequency and intensity of facial AUs. Several studies used the FACS to study pain in cognitively impaired (older) adults.[17-20] Pain stimuli were acute phasic pain by injection, and pain experienced on exercise after surgery. Both inter- and intrarater reliability were found to be moderate to high. Significant correlations were found between FACS scores and self-reported pain intensity, and small to medium correlations between FACS and another pain observation scale (Pain Behavior Method) were found for some items. All studies found significant differences between painful and painless situations, but no differences in pain scores between persons with and without analgesics. Defrin et al. applied the FACS in 159 adults with diverse cognitive impairments (CI), and measured pain at baseline and during vaccination.[21] Good interrater agreement, and inadequate to adequate internal consistency values were found. Scores during vaccination were significantly higher than at baseline, with less increase in the individuals with severe to profound CI than in the other groups. FACS was compared to another pain observation scale (NCCPC-R), and showed a medium correlation at baseline ($r = 0.37$) and a large correlation during vaccination ($r = 0.62$). A small correlation was found for self-report ($r = 0.12$). Overall, the FACS seems to be a reliable and valid tool, and an extended website on its use is available. However, the unidimensional focus on facial expressions seems disadvantageous, and its complexity to learn and use of video recordings make the FACS rather unsuitable for clinical practice.

The *Pain Behavior Method (PBM)* was developed to measure pain in chronic low back pain persons.[22] This observation system examines five pain behaviors (guarding, bracing, rubbing, grimacing, and sighing) during walking, shifting, sitting, standing and declining. Subjects are videotaped for 10 minutes, and recordings are later scored for presence or absence of each behavior. Hadjistavropoulos et al. studied the psychometric properties of the PBM in 58 older adults with cognitive impairments during exercise at a rehabilitation facility.[19] Overall interrater reliability was good, but ranged from poor to good in terms of specific behaviors. No significant correlation was found between PBM scores and self-reported pain intensity. PBM scores and FACS scores showed small to medium correlations. The PBM seems easy to use, for its conciseness and clear item

definitions. However, the use of video recordings makes this scale less feasible in clinical practice. Also, only three items (guarding, grimacing, and bracing) were found to be reliable in an older adult population with cognitive impairments, and no information on sensitivity to change and cut-off scores are not available.

The *Discomfort Scale-Dementia of Alzheimer Type (DS-DAT)* was developed to measure discomfort in patients with advanced dementia of the Alzheimer type.[23] The scale consists of nine items (two positive and seven negative), among others: breathing, vocalization, facial expression, and body language. After five minutes' observation (minimum 30 minutes after an intervention), the observer records frequency, intensity and duration of each item. Total score ranges from 0 (no discomfort observed) to 27 (high level of discomfort observed). The DS-DAT requires in-depth training with several practice opportunities. Both an English language and a Dutch version have been validated in Alzheimer patients, during presumably comfortable and uncomfortable situations or during acute illness, with sample size ranging from 19 to 97.[23-26] Interrater- and intrarater reliability were good, test-retest correlation was moderate, and internal consistency was adequate to high. Construct validity showed a significant correlation between DS-DAT and self-report by question, but no significant correlation with a self-report thermometer. Furthermore, DS-DAT-scores showed large correlations with the PAINAD observation scale, and DS-DAT showed higher scores in uncomfortable situations versus comfortable situations. In another study construct validity was indicated by medium to large correlations with scores on the Pittsburgh Agitation Scale.[27] Although several studies evaluated different aspects of reliability and validity, sensitivity to change and cut-off scores for discomfort still need to be established. Also, DS-DAT specifically focuses on measuring discomfort instead of pain, which are not interchangeable, because of different treatment protocols. The DS-DAT has a comprehensive scoring instruction and requires extensive training, which makes it less feasible.

The *Doloplus-2* scale from the French DOLOPLUS-Group, based on the Doloplus, was developed as a pain assessment instrument for nonverbal or cognitively impaired older adults.[28] It is based on observations of behavior (somatic, psychomotor, and psychosocial) in ten different situations that could potentially reveal pain. Scoring in a multidisciplinary team is preferable. With item scores ranging from 0 to 3, the total score may range from 0 to 30.[29] The instrument seems easy to use and takes only a few minutes to complete. The DOLOPLUS group has conducted a validation study among 143 patients in geriatric or palliative care units. No diagnoses or specific painful conditions were described. Interrater reliability was good, test-retest reliability showed acceptable to good correlations, and internal consistency was also good. In terms of construct validity, a large correlation was found between the Doloplus-2 and self-report. Medium correlations between the Doloplus-2 and different self-report measures in patients with dementia, as well as other pain scales were found in other studies.[30-32]

Table 2 Validity and Sensitivity

Instruments	References	Criterion Validity		Construct Validity		Sensitivity to change
		Concurrent: correlation between two pain scales	Concurrent: correlation between pain scale and proxy pain report	Convergent: correlation between pain scale and self report	Discriminant	Correlation between before and after pain medication
FACS	17 - 20	n = 58 PBM r = 0.02 (guarding) 0.13 (bracing) and 0.41 (grimacing)	n = 26 AU (frequency) r = 0.62 AU (intensity) r = 0.73	n = 55 CAS: r = 0.05 n = 82 CAS/VDS n = 12 CAS	n = 26 Higher frequency and intensity of of AU's during painful event n = 82 Significant higher scores during kneebending > standing > reclining	-
	21	n = 159 NCCPC-R r = 0.37 (baseline) r = 0.62 (vaccination)		FPS r = 0.12	baseline – vaccination: only significant difference for mild CI ($P < 0.001$), moderate CI ($P < 0.001$) and controls ($P < 0.01$); no significant difference for severe and profound CI	
PBM	19	n = 58 FACS r = 0.02 – 0.41	-	n = 55: CAS: r = 0.11 (bracing); r = 0.21 (guarding); r = 0.30 (grimacing)	n = 82 Significant higher scores during kneebending > Standing > Reclining	-
DS-DAT	23 - 26	n = 19 PAINAD: r = 0.76	n = 19 r = 0.56 (pain by VAS) r = 0.81 (discomfort by VAS)	-	n = 82 Higher scores during fever episodes compared with baseline scores. n = 46 Higher scores during uncomfortable situations (care- and transfer activities versus at rest)	-
	27	-	-	-	Pittsburgh Agitation Scale r = 0.51	-
Doloplus-2	29	-	-	n = 143 VAS: r = 0.65	-	-
	30		Pain ratings physicians			

			(NRS = 0 in 25 patients: 6 doloplus = 0/19 < 5); 10 doloplus scores < 5 and NRS > 0			
	31	n = 144 PACSLAC: pearson r = 0.29 PAINAD: pearson r = 0.34	VAS rater: r = 0.29 VAS nurse: r = 0.33	VRS: pearson r = 0.36		
		-	-	VAS/VRS/FPS: r = 0.31 - 0.40	-	-
	32	**-**	**-**	VAS: r = 0.38 (patients with dementia) Doloplus (5 item version) - VAS: r = 0.39	-	**-**
CNPI	33,34	**-**	**-**	n = 64 VDS: r = 0.30 at rest and r = 0.46 with movement	n = 26 Higher scores during movement compared to at rest	**-**
	35			VAS: r = 0.69 to 0.88		
	36	-	-	Self-report and number of pain behaviors: r = 0.49 and 0.47, *P* < 0.001	-	
Behaviour checklist	37	**-**	**-**	**-**	**-**	n = 13 Lower scores after pain medication
ADD	38, 39	**-**	**-**	**-**	**-**	n = 104 Fewer behavioral symptoms (*P* = 0.0001) n = 143 84% improved behavioral symptoms

Instruments	References	Criterion Validity		Construct Validity		Sensitivity to change
		Concurrent: correlation between two pain scales	Concurrent: correlation between pain scale and proxy pain report	Convergent: correlation between pain scale and self report	Discriminant	Correlation between before and after pain medication
PAINAD	41	n = 19 DS-DAT: r = 0.76	n = 19 r = 0.75 (pain by VAS); r = 0.76 (discomfort by VAS)	-	n = 19 Higher scores in unpleasant situations (F1,17) = 10.93	n = 19 Paired T-test: lower scores after pain medication (T(24) = 9.6, *P* < 0.001)
	31	PACSLAC: pearson r = 0.85 doloplus: pearson r = 0.34	VAS rater: r = 0.89 VAS nurse: r = 0.81 VAS video: r = 0.79	VRS: pearson r = 0.81	VAS-PAINAD: consistent upward trend in scores	
	43, 44	-	Signifcantly higher scores in patients who were in pain according to Global Pain Rating by nurses; Pain intensity-nurse: r = -0.01 and -0.05	-	r = 0.32 and 0.32 (Global Deterioration Scale) r = 0.02 and 0.07 (Apathy Evaluation Scale) r = 0.10 and 0.14 (Neuropsychiatric Inventory)	Lower scores after pain medication.
	42	-	VDS-nurse: r = 0.84, *P* = 0.001; categorical version PAINAD - VDS (nurse) (r = 0.85, *P* < 0.001)	VDS: r = 0.30, *P* = 0.005	r = 0.29, *P* = 0.005 (Cornell Scale for Depression in Dementia)	-
	45	-	-	VDS: r = 0.65, *P* = 0.008		
PATCOA	46	-	-	n = 116 VAS: r = 0.30	n = 116 Confusion: r = - 0.41	-
PADE	47, 48	-	-	-	n = 40 Agitation-scale: r = 0.30 - 0.42 Sign. higher scores in group 'pain is clinical factor'; No sign. differences between with and without painful conditions	Significant F-values for interaction between intervention and comparison groups
PACSLAC	49		n = 40 r = 0.39 and r = 0.54		n = 40 Significant differences between pain, calm and stress situations; r = 0.80 between two pain situations	-

	31	PAINAD: r = 0.85 doloplus-2: r = 0.29	VAS rater: r = 0.80 VAS nurse: r = 0.72 VAS video: r = 0.86	VRS: r = 0.81		
PACSLAC-D	50	PACSLAC: r = 0.95	-			
NOPPAIN	51	-	-	-	Bradley-Terry model: deviance GFI = 18.14 (10)	-
	52	PBM: r = 0.45 to 0.85	-	Impaired patients: NRS r = 0.16 VDS r = 0.05	-	-
Abbey pain scale	53	-	n = 61 Gamma = 0.59	-	-	n = 61 Sign. difference before and after intervention ($P < 0.001$)
PAINE	55	PAINAD: r = 0.23, P = 0.01 CNPI: r = 0.22, P = 0.05 PADE: r = 0.65, P = 0.001	Global Pain Rating (nurse): r = 0.54, P = 0.001 (n = 86) PADE (global questions): r = 0.42, P = 0.001 (n = 91)	n = 53 r = 0.24, P = 0.05; r = 0.15, P = 0.14	-	Significant F-values for interaction between intervention and comparison groups
EPCA-2	57	-	Global Clinical Score: r = 0.63 to 0.85 Dose of prescribed opioids r = 0.70 (n = 112)	-	Significantly higher scores in the opioid group compared to non-opioid group ($P < 0.0001$), and non-analgesics group ($P < 0.0001$)	r = 0.57 to r = 0.71 (change in scores and change in GCS after 48 hours); r = 0.62 (change in scores and change in opioid doses)
MOBID	58	-	-	-	Significantly higher pain scores were found during MOBID protocol than after regular care activities ($P < 0.005$); Negative correlations were found for MOBID and depression (r = -0.01) and neuropsychiatric disorders (r = -0.11)	-

FACS = Facial Activity Coding System; PBM = Pain Behavior Method;DS-DAT = Discomfort Scale – Dementia of Alzheimer Type; PAINAD = Pain Assessment in Advanced Dementia Scale; CNPI = Checklist of Nonverbal Pain Indicators; BC = Behaviour Checklist; ADD = Assessment of Discomfort in Dementia; PATCOA = Pain Assessment Tool in Confused Older Adults; PADE = Pain Assessment for the Dementing Elderly; PACSLAC (-D) = Pain Assessment Checklist for Seniors with Limited Ability to Communicate (-Dutch); NOPPAIN = Non-Communicative Patient's Pain Assessment Instrument; PAINE = Pain Assessment in Noncommunicative Elderly Persons;EPCA-2 = Elderly Pain Caring Assessment; MOBID = Mobilization-Observation-Behavior-Intensity-Dementia Pain scale; NCCPC-R = Non Communicating Children's Pain Checklist-Revised; AU = action unit; CI = cognitively impaired; CAS = Coloured Analogue Scale; VDS = Verbal Descrpitor Scale; VAS = Visual Analogue Scale; NRS = Numerical Rating Scale; VRS = Verbal Rating Scale; FPS = Faces Pain Scale; GCS = Global Clinical Score

As to feasibility and clinical utility, Doloplus-2 seems more difficult to use in daily practice than PACSLAC and PAINAD.[31] Holen et al. critized particularly the psychosocial items of the Doloplus-2.[30] Pautex et al. suggested that a five-item version, comprising two of the three psychosocial items and none of the psychomotor items, would be reliable and valid. They also found lower scores than the cut-off score of 5 in 57% of the patients with pain according to self-report.[32] Total scores 5 or higher are suggested to indicate pain, but the cut-off seems relatively low for a 0 - 20 scale, and how it was reached remains unexplained. A comprehensive website and instructional videotapes on the Doloplus-2 scale are available, both in French and English (www.doloplus.com).

The *Checklist of Nonverbal Pain Indicators (CNPI)* was designed to assess pain in cognitively impaired older adults in both acute and long-term care settings.[33] The checklist includes six behaviors, e.g. vocalizations, facial expression, and body language. The total score is the number of the behaviors present, thus ranging from 0 - 6. The authors suggest the instrument is easy to usy in clinical practice. Feldt et al. studied the psychometric properties in 88 cognitively impaired and intact hospital patients with postoperative pain.[33,34] Interrater reliability showed high agreement on the behaviors, the Kappa statistics were good to very good, and internal consistency was moderate. Medium correlations were found between the CNPI and self-report by the Verbal Descriptor Scale (VDS). Higher scores were found during activity than at rest. Nygaard et al. found fair to good inter- and intrarater reliabilities, and large correlations with self-report (VAS).[35] A cut-off score of 1 showed good sensitivity and specificity,[36] but seems somewhat low to use for presence of pain. Also, reliability and validity were not always that strong.

The *Behaviour Checklist* was developed for cognitively impaired older adults and consists of 20 items (e.g. moaning, quiet, crying easily, rocking).[37] Items are scored as present or absent. The authors conducted a double-blind intervention study in 13 cognitively impaired hospitalised patients showing pain. The Behaviour Checklist showed improved comfort levels after acetaminophen administration, which points at good sensitivity to change. However, only one study about the Behaviour Checklist was published, so more studies need te be done to confirm these preliminary results.

The *Assessment of Discomfort in Dementia (ADD)* was designed to assess and treat discomfort and pain in people with moderate to severe dementia.[38] The protocol consists of six behavioral categories to measure pain; facial expression, mood, body language, voice, and behavior. The observer scores the presence of behavioral symptoms. The authors studied the psychometric properties in (104 and 144) patients with dementia in long-term care facilities.[38,39] Interrater reliability was good. Significant differences in behavioral symptoms, as well as increased use of scheduled analgesics and non-pharmacological comfort interventions, point at sensitivity to change. In 88% of the cases, nurses reported the ADD protocol as

somewhat helpful to very helpful. In contrast with most other observation scales, the ADD protocol combines both observation of pain behavior with an ensuing treatment intervention plan for physical pain and/or affective discomfort. More extensive validation studies are still needed.

The *Pain Assessment in Advanced Dementia Scale (PAINAD)* was developed to measure pain in patients with (severe) dementia.[40] The scale consists of five items (breathing, negative vocalizations, facial expression, body language, and consolability). Each item is rated 0, 1 or 2, resulting in a total score from 0 (no pain) to 10 (maximal pain). Rating is by severity of existing behavior, with 0 for normal behavior, 1 more severe behavior and 2 most severe behavior. The instrument is easy to use after a 2-hour training session, and takes only a few minutes to complete. Nineteen patients with severe dementia were observed in rest, during a presumably pleasant activity (visit) and unpleasant activity (e.g. transfer).[41] Interrater reliability was good, and internal consistency ranged between inadequate to adequate. Large correlations were found between pain and discomfort measured by visual analogue scales and the PAINAD. Construct validity was confirmed by significant differences between the observed conditions, and by large correlations with DS-DAT scores. PAINAD-scores were significantly lower after analgesic administration. Overall, the sample size of the study was small, and somewhat low internal consistencies were found. In several other countries (the Netherlands, Singapore, Germany, Italy) the PAINAD has been validated, with varying results.[31,42-45] Regrettably, a cut-off score for pain is not provided.

The *Pain Assessment Tool in Confused Older Adults (PATCOA)* was developed and validated to assess postoperative pain in acutely confused older adults.[46] It includes nine cues in four categories (vocalizations, behaviors, motor activities, and facial expressions). Total score is the number of items present. The psychometric properties were studied in 116 hospitalised cognitively intact older adults with postoperative pain. Interrater reliability for the different items ranged from poor to good, and internal consistency was inadequate. As part of validity testing, the scale was correlated with a confusion scale and self-report, and showed medium correlations. Overall, published psychometric properties were weak and limited, and a cut-off score is not provided. Also, the PATCOA has been validated only in cognitively intact older adults undergoing orthopaedic surgery.

Villanueva et al. developed the *Pain Assessment for the Dementing Elderly (PADE)* to assess pain in patients with dementia.[47] The PADE assesses facial expressions, activities of daily living, and the caregiver's overall judgment of the resident's pain. The scale consists of 24 items in three categories: Physical, Global Assessment, and Functional. These items are rated on a visual analogue scale after 5 minutes' observation. In addition, 14 chart documentation data concerning the last 24 hours should be recorded. The authors suggest that completing the PADE requires five to ten minutes. Forty residents of long-term care facilities with advanced levels of

dementia who suffered potentially painful medical conditions were included in a validation study. Interrater reliability ranged from moderate to good, test-retest correlations ranged from low to good, and internal consistency coefficients for the subscales were inadequate (Functional part) to adequate (Physical part). Construct validity was indicated by medium correlations with scores on the Cohen-Mansfield Agitation Inventory. No significantly differences between groups with and without painful conditions were found, but significant higher scores were found in a group of patients in which pain was a significant clinical factor. Sensitivity to change was studied by Cohen-Mansfield and Lipson, and they found a significantly greater decrease in patients who received pain treatment compared to comparison groups.[48] The PADE showed a large range in reliability outcomes, dependent on the subscales, and validity were insufficiently tested. Time to complete is not known, and the complexity of some items, the variety in scoring, and the need to review chart documentation of the last 24 hours make the PADE probably less feasible in clinical practice.

The *Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC)* consists of 60 items in 4 categories (facial expressions, activity/body movements, social and personality changes, and 'other').[49] The category 'other' includes a variety of pain behaviors, e.g., appetite/sleeping changes. Subscale scores are derived from counting the checkmarks (present or absent) in each column. Summation of the four subscale totals generates a total pain score ranging from 0 - 60. In a preliminary validation study, patients with cognitive impairments were observed during two painful events, a non-painful distress event and at rest.[49] Interrater reliability was very good, and internal consistency was adequate to high. Concurrent validity was assessed by correlating nurses' ratings with rating for two painful events, which resulted in medium correlations. Furthermore, significant differences were found between painful and painfree situations. Mean completion time was 5 minutes. Clear instructions for use are available. The psychometric qualities of PACSLAC were also examined in a Dutch nursing home population with dementia.[31] Similar inter- and intrarater reliabilities, and internal consistencies were found. In addition, large correlations were found between PACSLAC and self-report (VAS, VRS) and PAINAD, indicating good criterion validity. A small correlation was found with Doloplus-2. In terms of feasibility, nurses preferred PACSLAC over PAINAD and Doloplus-2. Although PACSLAC overall shows good reliability and validity, the scale seems to include too many items for clinical use. Zwakhalen et al. reduced the 60-item scale into the PACSLAC-D with a three-component solution including 24 items.[50] This version has adequate levels of internal consistency. The correlation between the original PACSLAC and PACSLAC-D is large. Overall, PACSLAC-D has good psychometric properties, but the reasonably low cut-off score of 4 for pain on a possible total score of 24, asks for further testing.

The *Non-Communicative Patient's Pain Assessment Instrument (NOPPAIN)* focuses on pain assessment by caregivers in patients with dementia.[51] The scale rates the

following aspects: pain in response to activities of daily living, vocalisation and facial expression, bracing and restlessness, and a global rating of pain for that day. Subjects are observed during care activity, and the caregiver completes the NOPPAIN afterwards. Pictures facilitate use for caregivers with poor (English) language skills. Validity was studied using video recordings of an actress portraying a bed-bound patient with severe dementia during caregiving. Interrater reliability was good. Construct validity comparing ratings of caregivers with six videotaped pain levels was moderate. Especially differentiating between mild and moderate pain levels was difficult for the caregivers. A mean of 8 minutes (range 3 - 15) of caring and observing was found, and less than 30 seconds completion time. Horgas et al. presented good to very good inter- and intrarater reliability of NOPPAIN when used by nursing students.[52] For cognitively impaired patients, small correlations were found between NOPPAIN and self-reported pain intensity, and medium to large correlations between NOPPAIN and PBM. Overall, sensitivity to change and cut-off scores were not tested. Also, an actress portraying a patient with dementia as the gold standard of pain, has not been described in the literature as a reliable method.

The *Abbey pain scale* was developed to measure pain in people with end-stage dementia.[53] It includes six behavioral indicators, i.e. vocalization, facial expression, change in body language, behavioral change, physiological change, and physical change. While observing a patient, the observer rates the indicators as absent, mild, moderate or severe (0 - 3). The total pain score thus ranges from 0 – 18. Total scores 0 - 2 indicate no pain; 3 - 7 indicate mild pain; 8 - 13 indicate moderate pain; and 14 or higher indicate severe pain. Type of pain (chronic, acute or acute on chronic) can be noted. The Abbey pain scale is easy to complete and takes less than one minute. Abbey et al. (2004) validated the scale for 61 patients with end- or late stage dementia living in residential aged care facilities. The Abbey pain scale was completed when staff judged patients to be in pain. Interrater reliability was modest, and reliability analysis provided adequate to high internal consistencies. Concurrent validity showed a significant correlation between the pain score and a holistic pain assessment score by nurses. Furthermore, significant differences were found between pain scores before and after administration of analgesics. Van Iersel et al. examined its usefulness from reports of 185 care providers.[54] Fifty-six per cent agreed on measuring pain, 21% disagreed and 23% had no opinion. Fifty-five per cent agreed on easiness, 24% disagreed, and 21% had no opinion. More than 90% agreement about both 'easy to observe' and 'a good indicator of pain' was reached on: facial expression, vocalization, body language, physical changes. Indicators for which less than 60% agreement was reached were: behavioral and physiological signs. Overall, score ranges indicative of level of pain are given, but it is not clear how these were arrived at. Also, clear scoring instructions and item definitions are lacking.

Table 3 Reliability, feasibility, clinical utility

	References	Interrater/intrarater reliability	Internal consistency	Feasibility	Clinical utility
FACS	17 - 20	Interrater: 43 - 93% agreement (frequency); r = 0.82 - 0.97 (intensity); Intrarater: 79 - 93% agreement (frequency); r = 0.88 – 0.97 (intensity)	**-**	Requires special training; completion is time consuming; extensive information on website	**-**
	21	Interrater agreement: 0.80	α = 0.35 and 0.78		
PBM	19	Interrater: ICC = 0.10 – 0.87	**-**	Short scale; easy to use	-
DS-DAT	23 - 26	Interrater: Pearson r = 0.61 – 0.98 ICC = 0.74 Intrarater: ICC = 0.97	α = 0.77 to 0.89	Intensive training with several practice moments needed; rater training is provided	**-**
Doloplus-2	29	Interrater: paired t-test: no sign. differences between physicians (P < 0.001)	α = 0.82	Easy to use; lexicon and instructions for use are available; takes a few minutes to complete	Scores > 5 indicates presence of pain
	30	-	-	11 administrators: small administrative burden; pinpoints important pain cues; training and careful reading of the instruction manual needed for correct use.	Facial expression explained 48% NRS; 4 doloplus items explained 68% NRS; psychosocial items should be removed
	31	-	α = 0.58 to 0.80	Difficult to score and interpret	75% chose PACSLAC over PAINAD and doloplus; questionable if all items are relevant in detecting pain (psychosocial)
	32	Intrarater: ICC = 0.96	α = 0.67 (dementia)	Completion time on average 10 minutes (range 6 to 12)	57% of patients with pain according to self-report scored lower than 5
CNPI	33	Interrater: 93% agreement; κ = 0.63 – 0.82	α = 0.54 to 0.64	Easy to use	**-**
	35	Interrater: kappa 0.45 to 0.69 Intrarater: kappa 0.23 to 0.66	-	-	-
	36	-	-	-	Cut-off score = 1: sensitivity = 0.55 and specificity = 0.85

Behaviour Checklist	37	**-**	**-**	**-**	**-**
ADD	38, 39	Interrater: 76 - 100 % agreement	**-**	Education sessions, didactic instructions and site visits needed before using the protocol	Assessment and treatment /intervention plan in one
PAINAD	41	Interrater: Pearson r = 0.82 and r = 0.97	α = 0.50 to 0.72	Easy to use after minimal training; takes only a few minutes to complete	**-**
	31	Interrater 0.75 - 0.85; intrarater 0.89	α = 0.48 to 0.74	Userfriendly and not time-consuming (few minutes after they were used to the scale), but too concise	-
	43, 44	Interrater: r = 0.80	α = 0.85	-	**-**
	45	Interrater: Pearson r = 0.87, *P* = 0.001	α = 0.74	**-**	**-**
	54	-	-	185 care providers scored 157 non-verbal patients:52% agreed in measuring pain, 20% disagreed and 28% had no opinion. Forty-eight per cent agreed in easiness, 24% disagreed, and 28% had no opinion. More than 90% agreement about both easy to observe and a good indicator of pain accounted for facial expression, vocalization, and body language. Less good indicators were breathing and consolability (< 60% agreement).	-
PATCOA	46	Interrater: 56 - 100% agreement; Spearman rho = 0.16 – 1.00	α = 0.44	**-**	**-**
PADE	47	Interrater: ICC = 0.54 – 0.96	α = 0.24 to 0.88	Takes 5 to 10 minutes to complete	**-**
PACSLAC	49	Interrater: 94% agreement	α = 0.92	Takes approximately 5 minutes to complete	**-**
	31	Interrater ICC = 0.77 to 0.96 Intrarater ICC = 0.72 to 0.92	α = 0.10 to 0.84	75% of nurses preferred PACSLAC over PAINAD and Doloplus-2, because it was more user-friendly and not time-consuming	**-**
PACSLAC-D	50	-	α = 0.72 to 0.86	-	**-**

	References	Interrater/intrarater reliability	Internal consistency	Feasibility	Clinical utility
NOPPAIN	51	Interrater: kappa = 0.87; Pain level comparisons: 82 to 100% agreement	**-**	Mean of 8 minutes (range 3-15 min) to observe and complete; illustrations make use in practice easier	**-**
	52	Interrater: kappa = 0.72 to 1.00 (presence); ICC = 0.72 to 1.0 (intensity)/Intrater: kappa = 0.70 and 0.86 (presence), and ICC = 0.68 to 0.95 (intensity)	-	-	-
Abbey	53	Interrater: ICC = 0.63 and r = 0.44	α = 0.74 to 0.81	Easy to use; takes 1 minute to complete	-
	54	-	-	185 care providers scored 157 non-verbal patients; 56% agreed in measuring pain, 21% disagreed and 23% had no opinion. 55% agreed in easiness, 24% disagreed, and 21% had no opinion. More than 90% agreement about both easy to observe and good indicator of pain: facial expression, vocalization, body language, physical changes. Less good indicators (agreement less than 60%): behavioral and physiological signs	-
PAINE	56	Interrater: r = 0.99 and 0.71, P < 0.001 Intrarater: r = 0.78, *P* < 0.001	α = 0.78 and 0.75	-	-
EPCA-2	57	Interrater: ICC = 0.85 to 0.92	α = 0.73 and 0.75	Observation time had a mean of 4.8 minutes before caregiving, 5.2 minutes during caregiving, and completion time of 5.0 minutes	Observer must be familiar with the patient and usual behavior (= at least 3 observation days). A manual explaining rating of each item and the precautions is available
MOBID	58	Interrater: ICC = 0.70 to 0.90 (intensity); kappa = 0.05 to 0.84 (pain behaviors)	α = 0.90	-	-

Abbreviations: FACS = Facial Activity Coding System; PBM = Pain Behavior Method; DS-DAT = Discomfort Scale – Dementia of Alzheimer Type; PAINAD = Pain Assessment in Advanced Dementia Scale; CNPI = Checklist of Nonverbal Pain Indicators; BC = Behaviour Checklist; ADD = Assessment of Discomfort in Dementia; PATCOA = Pain Assessment Tool in Confused Older Adults; PADE = Pain Assessment for the Dementing Elderly; PACSLAC (-D) = Pain Assessment Checklist for Seniors with Limited Ability to Communicate (-Dutch); NOPPAIN = Non-Communicative Patient's Pain Assessment Instrument; PAINE = Pain Assessment in Noncommunicative Elderly Persons; EPCA-2 = Elderly Pain Caring Assessment; MOBID = Mobilization-Observation-Behavior-Intensity-Dementia Pain scale; ICC = intra class correlation coefficient

The initial development of the *Pain Assessment In Noncommunicative Elderly Persons (PAINE)* consisted of identifying a core group of pain behaviors that occurred in non-communicative nursing home residents according to nurses.[55] This resulted in specific repetitive motor behaviors, vocal behaviors, unusual behaviors, activity, and physical signs. Focussing on these behaviors, a two-phase study was conducted in nursing home residents with mild to severe dementia.[56] Internal consistencies were adequate, and inter- and intrarater reliability correlations were large. PAINE was correlated with several other pain measures to determine construct validity and showed small correlations with PAINAD and CNPI, and a large correlation with PADE. A large correlation was found for global pain ratings of nurses and a medium correlation for the global questions of PADE. Two self-reported scores were correlated with PAINE, and showed small correlations. PAINE's major asset is a comprehensive list of pain behaviors on the basis of systematic questioning of direct caregivers. Examining the sensitivity to change showed a significantly greater decrease in scores for patients who received pain treatment compared to comparison groups.[48] Overall, small correlations were found with other pain measures, and no further information is given about duration of completion and cut-off scores.[55]

The *Elderly Pain Caring Assessment 2 (EPCA-2)* was constructed to rate pain intensity in non-verbally communicating older patients.[57] The first version of the scale was based on the results of a survey among 48 experienced nurses and a literature review. The final version consists of 8 items, divided into two subscales. Both subscales contain 4 items, to be scored outside caregiving (facial expression, spontaneous posture adopted at rest, movements of the patients out of bed and/or in bed, interaction of all kinds with other people) and during caregiving (anxious anticipation of caregiver intervention, reactions during caregiver intervention, reactions when painful parts of the body nursed, complaints voiced in the course of caregiving). Each item is rated on a 5-point Likert scale, varying from 0 (no pain) to 4 (extremely intense pain), with a possible total score of 32. Both a French and English version of the EPCA-2 are available, but only the French version has been validated in non-verbally communicating older patients. Interrater reliability agreements were very good, and internal consistencies for both subscales were adequate. Convergent validity was measured by correlating EPCA-2 scores with a Global Clinical Score (GCS) as well as the dose of opioids prescribed by the physician, showing large correlations. A significantly higher EPCA-2 score was found in the opioid group compared to the non-opioid group, and the non-analgesics group, indicating good discriminant validity. In terms of sensitivity to change, large correlations were found for the change in EPCA-2 scores and the change in GDS after 48 hours as well as the change in opioid doses. No correlation was found between EPCA-2 scores and age, indicating good divergent validity since all patients were 65 years and older. Total observation and completion time is about 15 minutes. The observer must be familiar with the patient and his usual behavior, which indicates at least three successive observation days. A manual explaining the

rating of each item and the precautions is available. In conclusion, the EPCA-2 seems a well-studied, reliable and valid pain observation scale. The availability of two different language versions is an advantage for a broad use. Nevertheless, validity in an English-speaking population still needs to be examined. The mean duration of observing and completing the scale seems somewhat long compared to other pain observation scales. Also, a cut-off score for the presence of pain needs to be provided, together with a treatment protocol.

The *Mobilization-Observation-Behaviour-Intensity-Dementia (MOBID)* pain scale is a nurse-administered instrument developed for patients with a severe cognitive impairment.[58] The presence of pain behaviors (pain noises, facial expression and defense) should be observed during five standardized active guided movements together with a Numeric Rating Score (NRS) per movement for pain intensity. In addition, an overall NRS should be reported. In the development- and validation study of MOBID, 26 patients with severe cognitive impairment were observed and rated by the primary caregiver and external raters. After having received a 1-hour training, raters collected both bedside and videscores. Internal consistency was high and interrater agreements for pain intensity were good to very good, and for pain behaviors poor to very good. Significantly higher pain scores were found during MOBID protocol than after regular care activities. A large correlation was found between bedside and video scores. ANOVA analysis showed significant differences in pain intensity according to the number of observed pain behaviors, and the linear trend showed that higher number of pain behaviors indicated higher pain intensity. A high correlation was found between the separate pain intensities and the overall pain intensity. Negative correlations were found for MOBID and depression and neuropsychiatric disorders, indicating good discriminant validity. The MOBID provides evidence of good internal consistency and validity, despite the varying interrater agreements for pain behaviors. The results show evidence for using standardized movements in assessing pain, seeing that these yield significantly higher scores than do normal care activities. At the same time, this procedure is questionable as it elicits more pain than necessary. Furthermore, assessing daily pain is more rewarding. Regrettably, cut-off scores for pain, and associations with analgesics are lacking.

DISCUSSION

A great variety of observation scales have been developed to measure varying types of pain in varying groups of patients. Also, psychometric evaluation is not uniform among studies. For these reasons, it is difficult to determine which assessment is optimal.
A first distinction can be made in scales to be completed after a short period of observation, and scales to be scored over the preceding week, such as Doloplus-2, PAINE, and PADE. The choice of a scale therefore depends on the situation(s) for

which one wishes to assess pain. Scales of the first category seem more useful for relatively brief situations, such as washing or dressing. Scales of the second category are a good option in case of chronic pain. It should be noted, however, that regular application of observational scales could also provide insight in chronic pain.

Overall, the FACS, the PACSLAC, the DS-DAT, the PAINAD, and the EPCA-2 were most extensively studied, and show the most promising outcomes. Unfortunately, cut-off scores for these scales have not been established. Cut-off scores are important in deciding whether interventions to alleviate pain are required. They also appear to motivate nurses to assess their patients' pain. In view of the extensive training and analysing required for the FACS, the complexity of scoring and interpretation of the DS-DAT, and the large number of items in the PACSLAC, the PAINAD seems the best feasible scale for clinical practice. On the other hand, Zwakhalen et al (2007), comparing PAINAD, PACSLAC, and Doloplus-2, found that nurses rated PACSLAC as most useful. In addition, the feasibility of PACSLAC has been improved by the reduction to 24 items. In a Dutch nursing home population with dementia, the new version showed similar reliability and validity outcomes as PACSLAC, which resulted in a new scale, PACSLAC-D. The provided cut-off score of four for pain would seem to be somewhat low, however, and clear definitions of the behaviors are lacking.

Effective scale development in persons who are not able to report pain themselves is a challenge. While no 'gold' standard is available to validate an instrument in this population, one has resorted to 'silver' standards, i.e. proxy reports from caregivers or family members. Although it may be effective to use judgements of caregivers and family members who are familiar with the patient,[59] low agreement between patient's self-report and proxy reports was found, especially in the more severely cognitively impaired.[60] Caregivers and family members typically tend to underestimate (chronic) pain. Using self-report as a validation method requires a subsample of mildly cognitively impaired or intact persons, because most moderately to severely cognitively impaired people are not able to reliably report pain. Overall, varying results were found between self-report and pain observation.[19,29,61] Additionally, results concerning proxy reports and self-reports should be carefully interpreted and other standards should be considered, for example comparisons with existing observation scales to test concurrent validity. Thus, in developing new scales, observing patients – in particular during care activities when pain behavior is most likely or those patients who are likely to be in pain (e.g. postoperative patients, or osteoarthritic patients) – could be useful as part of the validation process. Furthermore, to achieve sufficient sensitivity to change, it is essential to demonstrate differences in scores between painful and painfree situations, and before and after changes in prescribed analgesics or other pain relieving therapies. Cohen-Mansfield and Lipson (2007) determined the utility of four pain assessment scales reported in this review (PAINAD, CNPI, PADE, and

PAINE) for analgesic use in persons with dementia, and concluded that PAINE and PADE were the strongest in detecting treatment effects.[48] Unfortunately, this conclusion was not based on well-established cut-off scores for pain.

As nurses tend to have limited time, a practical scale should be concise and easy to use. Clear definitions about type of pain and a scoring manual would make the assessment more useful. Information on the time needed to complete training sessions should be available.

Future goals

Differences in pain behavior and/or pain experience between patients with different types of dementia or different levels of cognitive functioning have been reported.[62,63] Therefore, we must be careful in interpreting results obtained in overall 'dementia' groups. Future research focusing on pain thresholds and pain tolerance levels in the older adults could give valuable information for the validation of a new scale. If we know the underlying pain thresholds and tolerances of different diseases, we can use these levels in order to measure pain more efficiently. The pain scores are then more reliable and with those a validation study is more reliable. Ideally, a new pain scale should be tested in various settings to improve external validity as well.

Lastly, in order to achieve less pain and better quality of life, pain scales should be linked with a treatment algorithm based on well-calculated cut-off scores. Importantly, pain should also be assessed after treatment to determine efficacy of treatment.

CONCLUSION

A reliable, valid and feasible pain scale enables to treat pain (more) adequately. As the available scales employ different methods of evaluating reliability and validity, and pursue different aims (e.g. type pain), they cannot easily be compared. More specific research is needed to develop a linked algorithm for pain treatment based on cut-off scores. Pain observation scales should at least be tailored to the unique characteristics and needs of the (older) adult with communication difficulties. Until a reliable and valid observation scale has been developed, patients with one or more probable painful diagnoses who are not able to communicate, should be treated as if they are in pain. In addition, we would recommend using the most promising pain scales to observe the presence of specific pain behaviors on a regular basis.

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5

In search of pain-indicating behavior in nursing home residents: the initial development of a pain observation scale

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Submitted

ABSTRACT

Background
Over a dozen observation scales are available to measure pain in elderly people with cognitive impairments. Considerably overlapping in content, they generally are not geared to non-verbal individuals with diagnoses other than dementia. We therefore aimed at identifying valid pain behaviors to form the core of a new pain observation scale for a wide range of cognitively impaired and non-verbal nursing home residents.

Methods
During two pain symposia participants identified from two validated behavioral children's pain scales those items that might represent pain expression in nursing home residents. Next, 8 trained raters scored videotaped behavior of 14 residents using a pool of 138 behaviors to identify the most valid ones. Scale development was by stepwise item selection. Behaviors assigned a mean score ≤ 0.10 were removed (step 1). Also, behaviors for which mean scores at rest were higher than or comparable to those in a painful situation were removed using Wilcoxon Signed Ranks test ($P > 0.05$) (step 2). Next, interrater agreement was estimated; behaviors for which intraclass correlation coefficient was < 0.30 were removed (step 3). Finally, we re-assigned the behaviors suggested during the pain symposia.

Results
Without adjusting, neither of the children's scales could be used in an older adult population. Forty-three of the 138 proposed items were removed in step 1, 86 in step 2, and two in step 3. Finally, seven behaviors were reinstated based on suggestions provided during the pain symposia. Therefore, 14 pain specific behaviors remained, i.e. 5 of the 33 in the category facial expression (15%), 4 of the 25 social-emotional behaviors (16%), 3 of the 17 vocalization behaviors (18%), one of the 37 motor behaviors (3%), and one of the 15 physiological signs (7%).

Conclusions
Fourteen behaviors showed to be promising as pain indicating behaviors, in terms of reliability and validity. In a next phase we will evaluate the interrelationships and the dimensional structure of these pain behaviors.

BACKGROUND

Surely the human being is neurologically equipped to exhibit a vast behavioral repertoire – also in expressing pain. Nevertheless, non-verbal patients may well be confined to a small repertoire of pain behaviors. Pain behavioral instruments for non-verbal patients, e.g. neonates, cognitively impaired and elderly with dementia, usually comprise a limited number of behavioral and psychological indicators of pain. Instruments for older adults mostly include facial expressions, verbalizations/vocalizations, body movements, changes in interpersonal interactions, changes in activity patterns or routines, and mental status changes, as advised by the American Geriatrics Society (AGS).[1] Although pain instruments have been studied for psychometric quality, most have only been tested in their construction phase.[2-4] Furthermore, most studies include only small numbers of severely cognitively impaired patients, and few data are available on pain prevalence in non-verbal patients other than with dementia, such as patients with severe aphasia or traumatic brain injury. Overall, the authors of reviews conclude that most instruments show moderate psychometric qualities, need further psychometric testing in clinical practice and that, therefore, not any instrument is yet available for broad adoption in daily clinical practice.

This study describes the phase of item selection in the construction of a new pain observation instrument for older adults with any kind of communication difficulties. In this phase, useful indicators of pain were identified based on two reliable and valid pain observation scales for children, the scale was drafted, and content and concurrent validity as well as reliability were evaluated. Our main question was: to what extent do nursing home residents exhibit pain-indicating behavior seen in non-verbal children?

METHODS

Participants

The study consisted of two parts. In the first part, we aimed to draw up an inventory of overt behavior that might represent pain expression in older adult nursing home residents. To this purpose we organized two pain symposia, and invited professionals of different disciplines, such as physicians, nurses, and physical therapists, of four nursing homes to attend and provide clinical input.

The second part aimed at identifying the most reliable and valid pain behaviors in practice. Five randomly chosen professionals (a nursing home physician, a nurse, a psychologist, a physical therapist and an occupational therapist) and three pain researchers rated video-taped behavior of 14 residents, i.e. 6 men and 8 women with a median age of 71 years (IQR 55 to 79). Nine residents could not express their pain verbally, due to severe dementia (n = 3), aphasia (n = 3), or acquired

brain injury (n = 3). The five others, residents who were rehabilitating in the nursing home from stroke or fracture(s), were able to verbally communicate. All residents were having chronic pain with a pain intensity level of 4 or higher according to their caregiving nurse and/or residents themselves.

Types of measurements

Two validated behavioral children's pain instruments were our starting point:

1. COMFORT behavior scale. Adapted from the original COMFORT-scale developed by Ambuel et al. by excluding the two physiological items, and validated for postoperative pain assessment for 0 to 3-year-old infants.[5] Interrater reliability of the COMFORT items proved to be good (Kappa 0.63 to 0.93) for all items except 'Respiratory response', for which it was moderate (Kappa 0.54). COMFORT 'behavior' was best represented with loadings from the behavioral items (Alertness, Calmness, Respiratory response/Crying, Physical movement, Muscle tone and Facial tension). Factor loadings of the items were invariant across time, indicating stability of the structure. The variables COMFORT 'behavior' and Visual Analogue Scale (VAS) pain were highly interrelated, thus indicating congruent validity. Each of the six items is scored from 1 to 5, resulting in a total score from 6 to 30. Higher scores indicate higher pain intensity.[6]

2. Checklist Pain Behavior (CPB) was developed to measure pain in children with a profound cognitive impairment. Its construction comprised several phases: the researchers started with a list of 138 items (CPB-138), representing specific behaviors, which was later reduced to 23 items, which were validated for postoperative pain.[7] Later, the researchers reduced this version to a 20-item version (CPB-20). Response categories for the CPB-138 and CPB-20 are different: for the first, responses range from 0 'never present' to 4 'always present', for the CPB-20 from 0 to 3. The higher the score, the higher pain intensity. In the first part of our study we used both CPB-20 and CPB-138 to compare both scales on feasibility and to establish content validity, i.e., to explore the extent to which all the relevant behaviors were identified that belong to the content domain of pain behaviors in nursing home residents. The aim of the second part was to identify those behaviors in nursing home residents that reflect most reliably and validly the experience of pain and those which do not. We therefore used CPB-138 only, because this automatically takes into account the CPB-20 items.

Procedure

In the first part of this study, we organized two pain symposia, in September and in October 2002. Each began with a short training session, i.e. plenary scoring of a nursing home resident's pain behavior from video. Participants were then asked to observe and rate three different recordings individually: one using COMFORT-scale

and CPB-138, one using COMFORT-scale and CPB-20, and one using CPB-20 only. These residents assumingly showed pain behavior, because they were in chronic pain according to their caregiving nurse and medical record, and were videotaped during a caring activity reported as (extra) painful. In addition, the experts were asked open questions about each instrument: which items do you consider as most important, which are superfluous and which important pain behaviors are not listed? The feasibility of the children's scales for use in an older adult population, in terms of completion time and clarity of format, was tested by the qualitative data collected during the pain symposia.

For the second part, fourteen nursing home residents referred to above (see Participants) were recorded in rest and while experiencing pain. Pain-eliciting situations (e.g. washing, dressing, physical therapy) were established by means of reports of caregivers and/or residents themselves. The five professionals referred to above were trained in rating the CPB-138. These persons and three pain researchers, experienced in observation of pain, independently observed the videos and rated the behavior.

Statistical analyses

Data were analyzed using SPSS 14.0.

Assuming that both children's' scales in their current form are not appropriate in our older population, we will use the combined results of both parts for item selection, beginning with the data of the second part (CPB-138). For the sake of content validity, items assigned a mean score ≤ 0.10, i.e., not or hardly observed, were removed. Next, to establish concurrent validity of the remaining items, items for which mean scores in the rest situation were higher than those in the painful situation were removed, as well as those for which these scores did not significantly differ between both situations using Wilcoxon Signed Ranks test ($P > 0.05$). Next, interrater agreement was estimated by calculation of the intraclass correlation (ICC) coefficient based on the two-way mixed model of absolute agreement. If the ICC was < 0.30, the item was removed.

To prevent premature removal of important behaviors, the items for which a trend was found in comparing painful and rest situations (*P*-value between 0.05 and 0.10) in combination with an ICC ≥ 0.30 were re-assigned to the item pool. In addition, behaviors judged to be specific pain behaviors in this population by more than 10 professionals during the pain symposia, were re-assigned as well.

In addition, sensitivity, and specificity of the remaining items in discriminating between the rest and the painful situation were assessed to determine predictive validity.[8]

RESULTS

Pain symposia

Thirty-eight participants (31 female), with a mean age of 38.9 years (sd 10.6), took part in one of the two pain symposia. They had a median of 10 years (IQR 4.9 to 21.5) of working experience in a nursing home, residential home or a hospital.

Scoring the videotaped sessions resulted in highest mean scores for facial expression (tense face, grimacing, frowning eyebrows, corners of mouth downward, fearful look), motor behaviors (tensed body) and vocalization (sounds of restlessness). Thirty-three participants completed at least one of the open questions about the pain instruments. Although none of the participants considered the instruments useful in an older adult population, the COMFORT was found less useful, and the CPB-20 was most preferred. Yet, 82% of the participants found the CPB-20 lacking in motor behaviors such as (unexpectedly) moving body parts, recurrent movements, and muscle tension. Ten of 32 (31%) reported crying in the COMFORT-scale as a relevant pain indicator. All six categories of the CPB-138 were found somewhat to very important: facial expression (100%), motor behavior (82%), vocalization (67%), social behavior/mood (67%), physiological signs (36%) and attitudes towards sore body part (27%). Within the categories, some of the participants reported specific behaviors, such as closing eyes, fearful look, seeking comfort, anger, agitation, moaning, specific sounds, and holding breath, as most important pain indicators. Overall, participants preferred the CPB-20 to the other instruments for its good feasibility, i.e. short time needed to complete and clear format. Additionally, 22% of the participants claimed advance knowledge about patients as a necessary prerequisite for observing and rating their behavior.

Item selection

Because none of the children's scales was considered useful for an older adult population, item selection was needed. This consisted of several statistical steps using data from both parts of the study. The first step in item selection was removing items reflecting behaviors (almost) never observed during a painful situation. This concerned 21 items not observed at all (Table 1a) and 22 items assigned a mean score of 0.10 or less (Table 1b). The next step was removing the 27 items for which scores at rest were higher than during the painful situation (Table 1c).

Fifty-nine of the remaining items did not significantly differ ($P > 0.05$) between the painful and rest situation, and were removed as well. Finally, two of the remaining 9 items had a lower ICC than 0.30, and were removed. At this point, seven items remained (Table 2).

Table 1a Items never observed during a painful situation (n = 21)

Item	Pain %	Rest %	Difference %
Stretching toes	0	0	0
Putting fingers in ear(s)	0	0	0
Hitting, pinching, scratching, biting	0	0	0
Destructive behavior (to material)	0	0	0
Head banging	0	0	0
Biting oneself	0	0	0
Hitting oneself	0	0	0
Pulling hair	0	0	0
Pulling (sore) body part	0	0	0
Taking clothes off	0	0	0
Snoring respiration	0	0	0
Blotched body	0	0	0
Ruminating	0	0	0
Putting fingers in mouth	0	0.9	-0.9
Grinding teeth	0	0.9	-0.9
Cyanotic (blue lips)	0	0.9	-0.9
Bending toes	0	1.8	-1.8
Scratching (sore) body part	0	1.8	-1.8
Hyperactive behavior	0	1.8	-1.8
Rolling eyes	0	3.6	-3.6
Looking pale	0	3.6	-3.6

Based on the Wilcoxon test, a trend was found in combination with an ICC of ≥ 0.30 in four items, namely frightened/fearful look, raising upper lip, sounds of restlessness, and holding breath, and were reinstated (Table 2). In addition, based on suggestions provided during the pain symposia, three more items (aggression/anger, seeking comfort, and crying) were added. The item pool at this point included 14 items.

Table 3 shows the sensitivity and specificity of these 14 remaining items. The percentual frequency of the presence of specific behavior during the painful situation (sensitivity) ranged between 0.11 to 0.65 and percentual frequency of its absence at rest (specificity) between 0.61 to 1.00 Several sensitivity values are low, which indicates that the items in question are not very often observed during a painful situation: considering their high specificity values, they also were hardly observed at rest.

Table 1b Items with a mean ≤ 0.10 in painful situation (n = 22)

Item	Pain %	Rest %	Difference %	Mean (sd) Pain
Yawning	0.9	0.9	0	0.01 (0.1)
Pointing at (sore) body part	1.8	1.8	0	0.04 (0.3)
Sucking	0.9	0.9	0	0.01 (0.1)
Sharp brief respiration	5.5	5.5	0	0.10 (0.5)
Lip biting	1.9	1.8	0.1	0.03 (0.2)
Striking movements	2.8	2.7	0.1	0.04 (0.2)
Stretching fingers	0.9	0	0.9	0.01 (0.1)
Perspiration	1.8	0.9	0.9	0.06 (0.4)
Clenching fists	3.7	2.7	1.0	0.09 (0.6)
Dozing, be half asleep	3.7	2.7	1.0	0.09 (0.5)
Withdrawing (sore) body part	3.7	2.7	1.0	0.07 (0.4)
Angry sounds	3.7	2.7	1.0	0.08 (0.5)
Hitting (sore) body part	1.8	0	1.8	0.02 (0.1)
Turning away from (sore) body part	3.7	1.8	1.9	0.06 (0.4)
Shocking respiration	3.7	1.8	1.9	0.06 (0.5)
Shivering	2.8	0.9	1.9	0.07 (0.5)
Tense tongue	3.7	0.9	2.8	0.07 (0.4)
Trembling leg, foot	2.8	0	2.8	0.04 (0.2)
Stretching leg	2.8	0	2.8	0.08 (0.6)
Blowing	2.8	0	2.8	0.08 (0.5)
Looking red, turning red	4.6	1.8	2.8	0.09 (0.4)
Growling	3.7	0	3.7	0.10 (0.5)

Considering the comparable findings in all analyses of the items 'squeezing eyes' and 'closing eyes almost', these items were combined into one. At last, we decided to create a new item, 'moving body part unexpectedly', because 82% of the participants of the pain symposia had singled this out as important pain behavior in the CPB-138 and as missing behavior in the CPB-20.

The item selection resulted in the following fourteen pain specific behaviors:

1. tense face
2. grimace
3. eyes (almost) squeezed
4. raising upper lip
5. frightened/fearful look
6. panicky, panics attack
7. not cooperating
8. seeking comfort
9. aggression/anger
10. moving body part
11. sounds of restlessness
12. moaning/groaning
13. crying softly
14. holding breath/faltering respiration

Table 1c Items with a negative difference between pain and rest (n = 27)

Item	Pain %	Rest %	Difference %
Moving head	37.0	51.8	-14.8
Moving arm	30.6	44.5	-13.9
Moving hand	35.2	48.2	-13.0
Being quiet	13.8	26.4	-12.6
Rubbing (sore) body part	3.7	13.6	-9.9
Other stereotypical movements	5.6	14.5	-8.9
Turning head away	7.4	14.5	-7.1
Wide-eyed	25.0	31.8	-6.8
Rubbing one's face	3.7	10.0	-6.3
(Paradoxical) laughing	3.7	10.0	-6.3
Warping mouth	4.6	10.9	-6.3
Stereotypic, repetitive behavior	10.1	15.5	-5.4
Motionless	19.4	24.5	-5.1
Chewing, smacking sounds	1.8	6.4	-4.6
Involuntary movements	13.0	17.3	-4.3
Rocking to and fro	3.7	7.3	-3.6
Motor restlessness	25.9	29.1	-3.2
Waving hands	0.9	3.6	-2.7
Active, lively	17.4	20.0	-2.6
Pressing lips together	22.2	24.5	-2.3
Looking sad, almost in tears	39.8	41.8	-2.0
Pulling clothes	0.9	2.7	-1.8
Coughing	2.8	4.5	-1.7
Fast respiration	3.7	4.5	-0.8
Listless, apathetic	11.9	12.7	-0.8
Restless head movements	15.7	16.4	-0.7
Moving trunk, back	13.0	13.6	-0.6

Table 2 Remaining items presented with Wilcoxon *P*-value and Intraclass correlation (ICC) coefficient (n = 68)

Item	Pain Mean (sd)	Pain %	Rest %	Difference %	Wilcoxon *P*	Reliability ICC
Facial expression						
Grimace	1.6 (1.6)	35.2	11.8	23.4	0.001	0.34
Closing eyes almost	0.5 (1.0)	25.0	7.3	17.7	0.01	0.31
Squeezing eyes	0.6 (1.1)	34.3	15.5	18.8	0.02	0.40
Tense face	1.6 (1.6)	64.8	39.1	25.7	0.02	0.35
Frightened / fearful look	0.9 (1.3)	39.8	24.5	15.3	0.08	0.54
Raising upper lip	0.4 (0.9)	18.5	6.4	12.1	0.08	0.48
Deeper nasio-labial furrow	1.2 (1.7)	42.6	30.9	11.7	0.40	0.27
Facial restlessness, tics	1.2 (1.5)	51.9	39.1	12.8	0.92	0.23
Trembling lips	0.4 (0.9)	23.1	9.1	14.0	0.11	0.20
Raising eyebrows	0.6 (1.0)	34.3	26.4	7.9	0.44	0.20
Frowning eyebrows	0.7 (1.2)	35.2	31.8	3.4	0.58	0.18
Pulling up nose	0.1 (0.5)	10.2	5.5	4.7	0.86	0.17
Mouth wide open	0.2 (0.7)	15.7	6.4	9.3	0.79	0.16
Pout	0.2 (0.7)	11.1	3.6	7.5	0.37	0.09
Continuous eye blinking	0.4 (0.9)	24.1	21.8	2.3	0.79	0.08
Corners of mouth downwards	1.2 (1.5)	51.9	39.1	12.8	0.67	0.07
Angry look	0.1 (0.6)	5.6	4.5	1.1	0.78	0.06
Clamping jaws together	0.2 (0.7)	14.8	6.4	8.4	0.58	0.04
Suddenly opening eyes	0.3 (0.7)	17.6	10.0	7.6	0.58	0.04
Pulling up chin	0.2 (0.8)	10.2	10.0	0.2	0.25	0.03
Pursing lips	0.2 (0.6)	9.3	2.7	6.6	0.81	0.02
Dejected, serious look	1.0 (1.4)	41.7	36.4	5.3	0.75	0.02
Moving nostrils	0.2 (0.7)	5.6	2.7	2.9	1.00	0.00
Trembling chin	0.3 (0.8)	12.0	10.9	1.1	0.43	0.02
Protruding tongue	0.1 (0.5)	7.4	4.5	2.9	0.32	ZV
Motor behavior						
Stiff, rigid	1.2 (1.6)	41.7	18.2	23.5	0.004	0.22
Trembling arm, hand	0.1 (0.5)	6.5	5.5	1.0	0.27	0.27
Moving leg	0.3 (0.9)	10.3	5.5	4.8	0.60	0.22
Changing position without help	0.5 (1.3)	17.6	12.7	4.9	0.29	0.14
Shaking movements	0.1 (0.6)	7.4	6.4	1.0	0.18	0.14
Tensed up	0.6 (1.2)	25.9	13.6	12.3	0.28	0.13
Stretching neck, head backwards	0.1 (0.7)	4.6	1.8	2.8	0.87	0.05
Raising shoulders	0.2 (0.6)	8.3	8.2	0.1	0.44	0.05
Stretching trunk, back	0.2 (0.2)	5.6	1.8	3.8	1.00	0.03
Poverty of motion	0.6 (1.2)	23.1	20.9	2.2	0.57	0.02
Limp	0.2 (0.7)	5.6	0.9	4.7	0.87	ZV

Item	Pain Mean (sd)	Pain %	Rest %	Difference %	Wilcoxon *P*	Reliability ICC
Huddling oneself	0.6 (1.2)	23.1	13.6	9.5	0.47	ZV
Moving feet	0.3 (1.0)	8.4	3.7	4.7	0.84	ZV
Pulling up knees	0.3 (1.0)	9.3	6.4	2.9	0.78	ZV
Stretching arm	0.1 (0.6)	5.6	3.6	2.0	0.66	ZV
Social and emotional status						
Panicky, panics attack	0.4 (1.0)	20.2	4.5	15.7	0.03	0.50
Not cooperating	0.4 (1.0)	14.7	1.8	12.9	0.05	0.30
Agitation	0.5 (1.0)	20.2	9.1	11.1	0.03	0.27
Restlessness	1.1 (1.4)	44.0	41.8	2.2	0.98	0.39
Sleepy, drowsy	0.3 (.8)	10.1	4.5	5.6	0.62	0.30
Aggression / anger	0.3 (0.8)	11.9	.9	11.0	0.13	0.29
Quiet	0.9 (1.5)	31.2	37.3	3.9	0.24	0.29
Inconsolable	0.3 (0.9)	13.8	3.6	10.2	0.26	0.28
Seeking comfort	0.2 (0.6)	11.9	5.5	6.4	0.66	0.23
Irritable	0.4 (0.9)	17.4	3.6	13.8	0.25	0.22
Resistant	0.4 (0.9)	17.4	3.6	13.8	0.15	0.21
No interaction	0.9 (1.5)	31.2	27.3	3.9	0.97	0.13
Accepting comfort	0.4 (1.0)	21.1	10.9	10.2	0.32	0.11
Refusing physical contact	0.1 (0.6)	4.6	0.9	3.7	0.73	0.01
Attitude towards sore body part						
Holding on to (sore) body part	0.1 (0.4)	10.1	8.2	1.9	0.33	0.10
Protecting (sore) body part	0.2 (0.6)	10.1	5.5	4.6	0.81	0.07
Vocalization						
Moaning, groaning	0.8 (1.3)	36.7	7.3	29.4	0.00	0.55
Sounds of restlessness	0.4 (1.0)	14.7	4.5	10.2	0.08	0.43
Crying softly	0.2 (0.7)	11.0	0	11.0	0.15	0.58
Screaming, yelling	0.2 (0.7)	9.2	3.6	5.6	0.78	0.36
Stereotypic, repetitive sounds	0.5 (1.1)	16.5	9.1	7.4	0.85	0.31
Guttural, throaty sounds	0.3 (0.9)	10.1	5.5	4.6	0.91	0.12
Crying loudly	0.1 (0.6)	4.6	1.8	2.8	0.61	0.10
Babbling	0.5 (1.0)	21.1	18.2	2.9	0.63	0.04
Physiological signs						
Holding breath, faltering respiration	0.2 (0.7)	12.8	1.8	11.0	0.07	0.30
Tears	0.1 (0.6)	5.5	0	5.5	0.87	0.24
Gasping	0.2 (0.7)	8.3	6.4	1.9	0.53	0.24
Looking ashen	0.1 (0.7)	4.6	2.7	1.9	0.59	0.08

ZV = zero variance; P ≤ 0.05 and ICC ≥ 0.30; P ≤ 0.10 and ICC ≥ 0.30

Table 3 Sensitivity and specificity of the final 14 remaining items

Item	Sensitivity	Specificity
Tense face	0.65	0.61
Grimace	0.35	0.88
Raising upper lip	0.19	0.94
Squeezing eyes	0.25	0.93
Closing eyes almost	0.34	0.85
Not cooperating	0.15	0.98
Panicky, panics attack	0.20	0.95
Frightened/fearful look	0.40	0.75
Seeking comfort	0.12	0.95
Aggression/anger	0.12	0.99
Moaning, groaning	0.37	0.93
Sounds of restlessness	0.15	0.95
Crying softly	0.11	1.00
Holding breath/faltering respiration	0.13	0.98

DISCUSSION

In the present study we explored behavioral indicators of pain in a nursing home population as a first phase in constructing a new observation scale to assess pain. Starting out with pain scales for children, we concluded that children's pain behavior could not be extrapolated directly to an older adult population. Corresponding behaviors were present, but did not seem to cover the whole spectrum of pain behavior at the end of life. Therefore, we decided to identify from a pool of as many as 138 items those that are indicative of pain in an older population. Clinicians who work with older adults and researchers who study (pain) behavior could benefit from our findings. Our results could be compared with existing pain scales or could be the starting point for new instruments.

Pain indicators

Overall, facial expression was considered the most important pain behavior. In particular the items tense face, grimacing, closing eyes, and fearful look were judged relevant pain indicators. These specific items have also been found in children and other adult populations.[7,9,10] Several studies support the validity of using facial expression in detecting pain, both in older people with and without cognitive impairment.[9,11] We would like to point out, however, that wrinkles and other facial aging signs might make it difficult to observe facial expression in the elderly. This is particularly so in patients with Parkinson disease, as they show rigidity of their (facial) muscles and a continuously tensed face. In addition, in a study of Defrin et al. (2006), adults with severe to profound cognitive impairment did not show more facial activities during an acute pain situation than at baseline.

But other pain indicators did differ between the two situations.[12] It would, therefore, be advisable not to focus on facial expressions solely. The participants of the symposia felt motor behavior to be missing in the Checklist Pain Behavior (CPB), and this item therefore was included in our scale. Older persons appear to use more motor behavior in expressing themselves than do children with profound cognitive impairment. Moreover, the category 'body movements' is also one of the relevant pain indicators according to the American Geriatrics Society (AGS) guidelines. Except for the category 'Changes in activity patterns of routines', the other categories as described by the AGS are all filled with the behaviors we found useful in our study. In our opinion, the first category could be the first signal to begin with pain assessment. Only one other study used a pain scale for children in older adults, namely the Face, Legs, Activity, Cry, and Consolability (FLACC) pain assessment tools.[13] Besides the limited number of six subjects, reliability and validity of the scale were not sufficient. In addition, like the Pain Assessment In Advanced Dementia (PAINAD),[14] which has been adapted from the FLACC, relevant categories of the AGS guidelines are lacking.

We acknowledge that several of the maintained items always occurred simultaneously, for example when seeing a grimace, tense face is also present. Still, our results show that tense face as a specific pain indicator can also occur by itself.

A methodological weakness of our study is that we do not know with certainty whether the non-verbal participants experienced pain during the video recording. Practical and ethical considerations, however, prevented us from exposing the residents to more pain than necessary. Using daily care activities, we wanted to capture the more chronic pain behavior, which is much more prevalent in older adults than acute pain, and which is particularly exposed during such situations.[15,16]

Another consequence of the recording of daily care activities is the relatively low between-subjects variance in the pain scores. As the ICC is strongly influenced by the variance of the trait in the population in which it is assessed, the ICCs we observed were 'artificially' deflated. Another explanation for these low ICCs might be the limited training in scoring the specific behaviors – a more elaborate training program would very likely have resulted in a higher interrater agreement. Therefore and to prevent overfitting we choose the relatively low cut-off value of 0.30 for the ICC-coefficient.

Individualized approach

This study concerned nursing home residents with different medical backgrounds and different cognitive levels. Therefore, questions could be raised about possible differences in pain behavior. Although facial expression, as one of the most important pain behaviors, has proven to be universal,[17-19] we certainly acknowledge individual differences between residents. We therefore recommend an individual

approach, next to the use of a standardized valid pain instrument, because hardly any specific behavior exclusively indicates the experience of pain. For example, introverted behavior in demented patients can indicate pain and/or be a symptom of the existing dementia or a depression.

Closs et al. found three types of behavioral indicators of pain, namely verbal and body language cues, acute behavioral cues, and general behavioral changes.[20] The first two types can be related to the behaviors we found by observing the patient directly. Nurses and physicians need to be trained in recognizing the specific behaviors before they can objectively assess pain. Videotapes of nursing home residents exhibiting the behaviors in question could be very helpful. The relevance of training is underlined by Prkachin et al. who showed that untrained observers tend to underestimate patients' pain more than trained observers.[21] The general behavioral changes that Closs et al. found as indicators of pain are highly relevant, but can not be identified in a short bed-side observation. We nevertheless believe that such changes, for example in sleeping- or eating pattern or in emotional state, should alert caregivers to the desirability of objective pain measurement using a pain observation scale.

CONCLUSIONS

Fourteen behaviors showed to be promising, both in terms of reliability and validity, for measuring pain in a nursing home population with a wide range of cognitive levels. In a next phase we will evaluate the interrelationships and the dimensional structure of these pain behaviors and they will be further tested on their psychometric properties in a larger sample of older adult nursing home residents with varying backgrounds and cognitive levels.

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6

The Rotterdam Elderly Pain Observation Scale (REPOS); a new behavioral pain scale for non-communicative adults and cognitively impaired elderly

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ABSTRACT

Background
Several observation scales have been developed to measure pain in elderly persons with cognitive impairments. Most scales, however, do not provide cut-off scores for pain, and previous studies do not include data on non-verbal patients with diagnoses other than dementia.

Objective
The development of an easy-to-use, reliable and valid pain observation scale, the Rotterdam Elderly Pain Observation Scale (REPOS), for use in nursing home residents incapable of reporting pain themselves.

Methods
In this multicenter case-control study 174 residents of various cognitive levels were videotaped at rest and during a potentially painful activity. Prevalences and co-occurrences of behaviors were examined, and interrelationships were identified. To reduce number of items, multiple linear regression analysis was used. Interrater-, and intrarater agreements and internal consistency were investigated. To estimate validity, REPOS was related to Numeric Rating Scale (NRS) and Pain Assessment in Advanced Dementia-Scale (PAINAD), and activity and rest situations were compared.

Results
A one-dimensional model with a good fit was found. After redundancy analysis, ten items remained. Interrater- and intrarater agreements of two observers were good. Internal consistency was moderate. Correlations between REPOS and NRS were small to medium, and between REPOS and PAINAD large. REPOS-scores for the two situations differed significantly. A total score of 3 and higher indicates pain.

Conclusions
REPOS appears to be promising for identifying pain in residents of various cognitive levels. To improve pain management, a cut-off score for pain was determined, together with a treatment protocol. Its conciseness suggests good usefulness in daily practice.

INTRODUCTION

Pain assessment and management in older adults is challenged by misconceptions, communication problems, difficulty of chronic pain treatment, polypharmacy and comorbidities.[1,2] Especially, cognitively impaired and non-verbal older adults are at high risk for undertreatment of pain.[3,4] When self-report is impossible, behavioral assessment is advocated. Up to a dozen behavioral observation instruments have been published by now. Recent reviews, however, point out that most of these instruments show moderate psychometric qualities for older adults and need further psychometric testing. Therefore, none of them as yet qualifies for broad adoption in daily clinical practice.[5,6] Some instruments revealed differences in pain behavior between patients with and without cognitive impairments.[7,8] In addition, while pain experiences seem to differ for various types of dementia, the instruments mostly focus on dementia in general, or on a specific type of dementia.[9] Furthermore, most of these instruments have been tested in mildly cognitively impaired patients only. Previous studies generally lack data on chronic pain behavior in non-verbal patients with diagnoses other than dementia, such as stroke and acquired brain injury. We felt, therefore, a need for a pain observation instrument for various non-verbal populations other than only patients with dementia. In an earlier, explorative study we constructed a set of fourteen pain behaviors typically seen in nursing home residents. The objective of the present study was to develop an easy-to-use, reliable and valid observation instrument to measure pain in nursing home residents for whom self-report is impossible.

METHODS

Design

This is a multicenter case-control study. The Erasmus MC Medical Ethical Review Board approved the study, and so did directors and client boards of the nursing homes involved.

Participants

Residents from somatic, rehabilitation and psychogeriatric wards of six nursing homes in the Netherlands were screened for eligiblity. The inclusion criterion was a nurse's rating of 4 and higher on a numerical rating scale (NRS) from 0 to 10 – indicating moderate to severe pain – of the resident's pain in the preceding weeks.[10] Either residents themselves or legal representatives signed written informed consent.

Participants were post-stratified into a case group or a control group on the basis of cognitive status as assessed by the MMSE. The case group comprised moderately to severely cognitively impaired residents (MMSE < 18) as well as residents who were verbally unable to communicate at all (impossible to administer MMSE). The control

group included cognitively intact to mildly impaired residents (MMSE ≥ 18), who could report their pain themselves.

Measures
Demographic and medical data were extracted from medical charts. Classification of most painful diagnoses was in conformity with the WHO International Classification of Diseases (ICD-10, 1994).

Cognitive status was assessed by Mini Mental State Examination (MMSE), a valid instrument for older adults. The 11 MMSE-items yield a total score ranging between 0 and 30. Scores 0 to 9 indicate severe cognitive impairment, 10 to 17 moderate cognitive impairment, 18 to 23 mild cognitive impairment, and 24 to 30 no cognitive impairment.[11]

Performance status was assessed by the Karnofsky index. Scores range from 0, representing deceased, to 100, representing normal situation without complaints.[12]

Pain measures
In a previous explorative study a panel of experts identified fourteen behaviors out of a pool of 138. This was the result of a stepwise item reduction procedure based on videotaped observation of residents in rest and in a potentially painful situation. Scores on these fourteen behaviors were found to be significantly higher in the potentially painful situation. The preliminary Rotterdam Elderly Pain Observation Scale (REPOS) included:

1. tense face
2. grimace
3. eyes (almost) squeezed
4. raising upper lip
5. frightened/fearful look
6. aggression/anger
7. panicky, panics attack
8. not cooperating
9. seeking comfort
10. moving body part
11. crying softly
12. moaning/groaning
13. sounds of restlessness/verbal expressions
14. holding breath/faltering respiration

Scoring was on a four-point scale: 0 = 'not present', 1 = 'sometimes present', 2 = 'often present', to 3 = 'always present'; theoretically, the total score ranges from 0 to 42.

The Numeric Rating Scale (NRS) rates pain intensity from 0 ('no pain') to 10 ('worst possible pain'), and was found a reliable and valid pain assessment in older adults with varying cognitive levels.[13] In the current study, the ratings of nurses (NRS-nurse) and those of residents themselves if feasible (NRS-resident) served to establish convergent validity.

Pain Assessment in Advanced Dementia (PAINAD) scale was used to establish congruent validity. This five-item observation instrument was developed to measure pain in patients with (severe) dementia.[14] Items are scored 0, 1 or 2, resulting in a total score from 0 ('no pain') to 10 ('maximal pain'). For our research purposes PAINAD was translated into Dutch, according to the backward-forward principle. The Dutch version proved reliable and valid.[15]

Procedure

The first researcher (RvH) learned to observe pain behavior and interrater agreement between her and a trained pain specialist was 0.84. A research-assistant learned to observe pain behavior on the guidance of the definitions of the REPOS items and made ten observations in older adults to establish good agreement with the first researcher.

The caregiving nurses identified those residents who had experienced moderate to severe pain in the preceding weeks (NRS ≥ 4). Either the researcher or research-assistant made video recordings of a potentially painful activity such as being washed or dressed, and a rest situation. Directly after a recording both the resident's nurse and the resident, if possible, rated the experienced pain intensity. Within a month, a two-minutes episode of each recording was observed and scored with the 14 item-REPOS and PAINAD. To estimate the interrater agreement, both researchers independently scored the behavior of 31 randomly selected residents. The remaining residents were scored by one of the researchers.

Intrarater agreements of both researchers were estimated over fourteen randomly selected recordings, at a month's interval between the two scoring moments. During scoring of the videotapes researchers were naïve for resident's medical condition and analgesics use. On the day of recording, the resident's cognitive status was assessed by MMSE. Details of resident's medical condition and analgesics use were later extracted from the medical and nursing records.

Statistical analyses

The categorical data are expressed as percentage, as a measure of central tendency. For the continuous data, either mean and standard deviations (sd) are presented for normally distributed variables, or median and inter quartile ranges (IQR) for not normally distributed variables. Chi-square test and Fisher's Exact test were applied for categorical data, and Mann-Whitney U test and Independent Samples T-Test for continuous data to estimate associations between case and control groups.

The level of significance was set at 0.05 (two-tailed). Data were analyzed with SPSS 14.0.

Behaviors
First, co-occurrences and prevalences of the 14 behaviors during an activity were calculated in percentages. Behaviors with a prevalence not exceeding 5% were eliminated.

Activity scores were analyzed by multiple logistic regression analysis, adjusted for gender and age, to identify differences on individual items with case and control group as criterion variable. The odds-ratio (OR) and 95% confidence intervals (CI's) served as measure of individual performance.

The interrelationships of the REPOS items in terms of a clinical-empirical structure were identified with the computer algorithm PROXSCAL (short for Proximity Scaling). To determine the best fitted model without substantial loss of information, both a one- and two-dimensional solution were carried out. The quantifications (in terms of z-score) of the individual variables indicate the degree of individual performance. As a measure of model performance the Normalized Raw Stress was chosen. Ideally, this coefficient should be < 0.05. Additionally, the Tucker's φ coefficient of congruence was the measure of correspondence between the Euclidean distances of the data and the distances derived from the model identified. This coefficient should be > 0.95.

Redundancy
In view of possible item reduction, we explored qualities in predicting the total score by means of multiple linear regression analysis with total score as outcome variable and individual items as predictor variables. This strategy aims to establish the minimum number of items required to predict the outcome, without substantial loss of information. The explained variance needed to be 90%; redundant items were eliminated. The findings from these analyses will result in the final REPOS scale.

Reliability and validity estimates
We determined reliability and validity estimates of the remaining items.
Interrater- and intrarater agreements were measured by means of intraclass correlation (ICC) coefficients using the two-way mixed model.[16]

Scale reliability was estimated using the Kuder Richardson coefficient (KR20), as the scored items were recoded from four to two response categories.[17]

Convergent validity was estimated by correlating REPOS with NRS-resident and NRS-nurse using the Spearman Rank correlation coefficient with 95% CI. Congruent validity was estimated by correlating REPOS with PAINAD using Spearman Rank correlation test (r_s) with 95% CI, for case and control group separately as well as for activity and rest situation separately. Cohen's criterion to judge the value of correlation coefficients is: 0.10 to 0.29 (small r); 0.30 to 0.49 (medium r); and ≥ 0.50 (large r).[18] A two-way ANOVA with repeated measurements on the total

REPOS score was performed to test any differences between case and control group (differential validity) and activity or rest (sensitivity to change). For significance testing the F-statistic was used.

Any differences in activity scores between two subtypes of dementia, namely Alzheimer and vascular dementia, were investigated with the Chi-square test on item level (differential validity).

To optimally differentiate between activity and rest, the cut-off score at which the combination of sensitivity and specificity was highest for both case and control group was calculated.[19]

RESULTS

Residents

In total, 223 residents or their legal representatives were invited to participate. Participation was refused in 29 cases and 8 residents died before start of the study. For 12 of the remaining 186 residents, NRS-nurse was < 4.0 and they were, consequently, excluded. The final sample of 174 participants (110 female/64 male) had median age of 82 years (IQR 73 to 87), and median nursing home stay of 16.5 months (IQR 5 to 38).

The case group included 124 residents, for 69 of whom MMSE was not completed (56%): sixty-seven were unable to verbally communicate at all, and two scores of residents were missing. Self-report was not possible or not reliable for these 122 residents due to severe dementia (n = 73), cognitive limitations (n = 10), severe aphasia (n = 26), sedation (n = 5), sub-comatose condition (n = 4). The control group included 50 residents (Figure 1). In both groups, musculoskeletal and circulatory symptoms most frequently induced painful conditions. Demographics, most painful diagnoses and prescribed analgesics are presented in Table 1.

Behaviors

All 174 residents were observed during an activity, and 172 at rest.
Prevalences of almost all behaviors were either 0 (never present) or 1 (sometimes present). For all other items, except tense face, the answer category 'sometimes' was much more frequent than 'often' and 'always' together. For this reason, the 0 to 3 range was dichotomized by recoding 'never present' into 0 and other categories into 1. The correlation between the total scores of the 0 to 3 scale and the total scores of the dichotomized version was large ($r_s = 0.88$).

The matrices of prevalences and co-occurrences (Table 2) demonstrate that tense face was always present. The prevalence of crying was less than 5%, and this behavior, consequently, was eliminated. Ninety-four percent of the residents showed at least two pain behaviors, and 88% at least three.

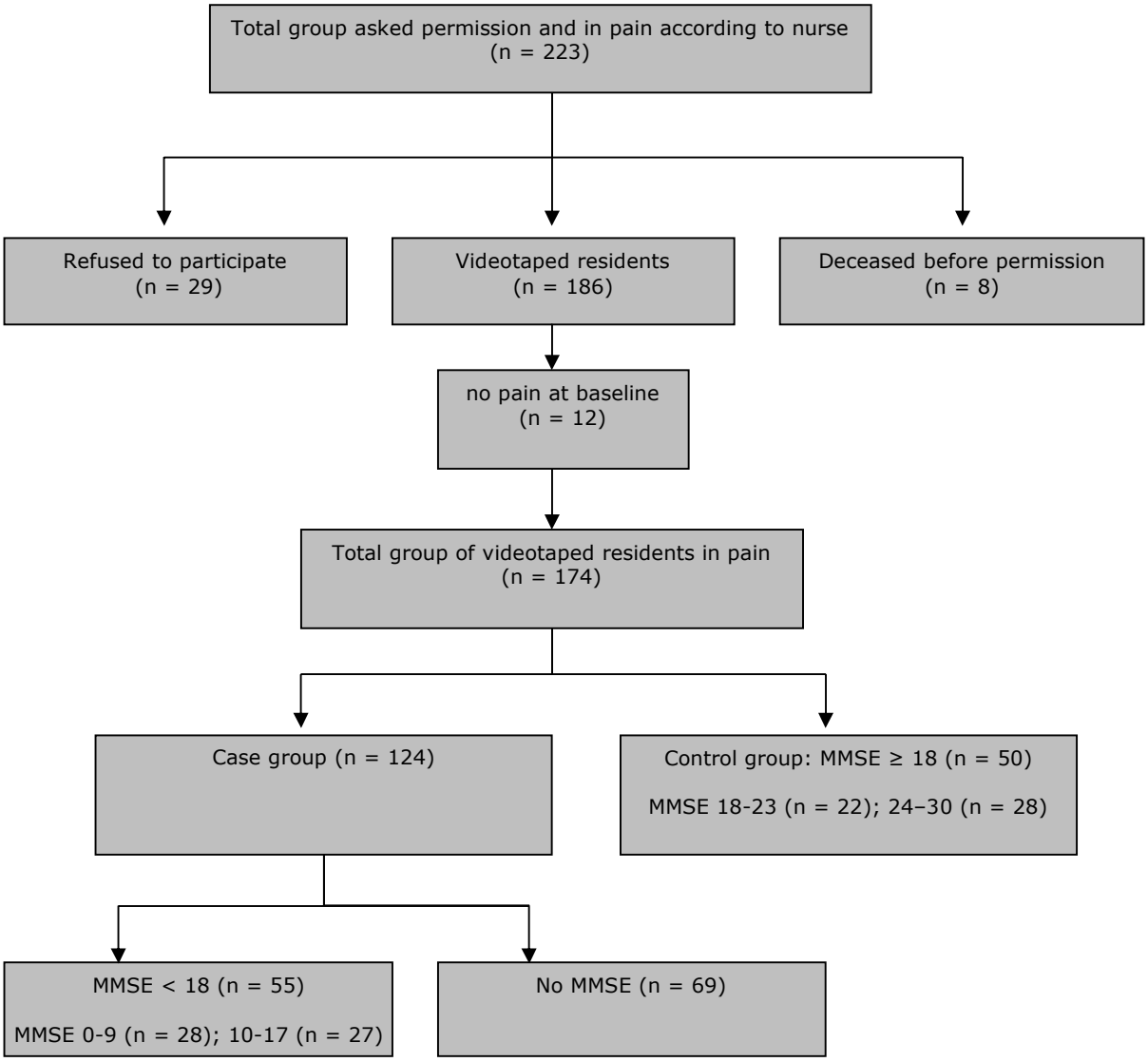

Figure 1 *Flow chart of participants*
MMSE = Mini Mental State Examination

Multiple logistic regression analysis on the activity scores revealed significant higher scores for the case group on three items: panicky, panics attack (OR = 3.67, *P* = 0.01), aggression/anger (OR = 11.73, *P* = 0.02), and moaning/groaning (OR = 3.13, *P* = 0.01) (Table 3).

PROXSCAL multidimensional scaling revealed no substantial differences in the empirical structure and the model fit between case and control group. Normalized Raw Stress values were 0.03 and 0.01, respectively for case and control group, and the Tucker's coefficient was 0.99 for both groups. This justified combining these groups in the next analyses. Furthermore, both the one- and two-dimensional solution showed a good fit, with a Normalized Raw Stress value of 0.02 and 0.01, respectively, and a Tucker's coefficient of 0.99. Because of the principle of parsimonious modeling, the one-dimensional solution was the preferred choice (Table 4).

Table 1 Demographic and medical variables

	Case group n = 124	**Control group n = 50**	***P*** [1]
Gender n females (%)	84 (68)	26 (52)	0.08
Median age (IQR)	83 (74 to 89)	78 (70 to 84)	0.02
Mean MMSE (sd)	9.6 (5.1)	23.7 (4.0)	0.00
n (%)	55 (44)	50 (100)	
Median Karnofsky (IQR)	50 (40 to 50)	60 (50 to 60)	0.00
Median length of stay in months (IQR)	24 (6 to 45)	9 (2 to 18)	0.00
Pain diagnoses n (%)			
musculoskeletal system	52 (42)	23 (46)	0.53
circulatory system	30 (24)	15 (30)	
skin and subcutaneous tissue	19 (15)	3 (6)	
nervous system	6 (5)	5 (10)	
injury, poisoning etc	7 (6)	2 (4)	
neoplasms	3 (2)	-	
digestive system	1 (1)	1 (2)	
genitals	2 (2)	-	
external causes	3 (2)	1 (2)	
Unknown	1 (1)	-	
Highest prescribed analgesics n (%)			
None	30 (24)	5 (10)	0.32
Step 1 routine	54 (44)	24 (48)	
Step 2 routine	11 (9)	6 (12)	
Step 3 routine	11 (9)	6 (12)	
As needed [2]	18 (14)	9 (18)	

[1] two-tailed; [2] residents receiving only as needed pain medication in one of the WHO steps
Abbreviations: IQR = Inter Quartile Range; MMSE = Mini Mental State Examination; sd = standard deviation

Redundancy

Multiple regression analysis with the 13 items sum score as outcome revealed that ten of the thirteen items jointly explained 92% of the variance. Consequently, the other three items i.e. not cooperating, aggression, and seeking comfort, were eliminated. The final scale thus comprises 10 items and is further referred to as the Rotterdam Elderly Pain Observation Scale (REPOS) (See Appendix).

Reliability and validity estimates

All reliability and validity outcomes are estimated for the dichotomized final 10-item version.

Table 2 Prevalences and co-occurrences of 14 pain behaviors in all patients and according to case and control group

	TF	G	FL	CE	RL	MB	P	NC	SC	A	C	M	S	HB
Matrix of co-occurrences of pain behaviors in all residents (n = 174), %														
Tense face (TF)	**100**													
Grimace (G)	40	**40**												
Fearful look (FL)	30	11	**30**											
Closing eyes (CE)	79	40	20	**79**										
Raising upper lip (RL)	58	33	15	53	**58**									
Moving body part (MB)	28	14	8	25	16	**28**								
Panicky (P)	24	9	10	19	12	13	**24**							
Not cooperating (NC)	11	8	5	9	8	5	5	**11**						
Seeeking comfort (SC)	19	6	9	16	9	7	6	2	**19**					
Aggression (A)	13	8	5	11	7	10	8	5	2	**13**				
Crying (C)	1	1	0	1	1	0	0	0	0	0	**1**			
Moaning/groaning (M)	37	15	12	32	22	13	14	6	7	6	1	**37**		
Sounds/verbal (S)	20	8	5	17	13	9	10	3	5	6	1	8	**20**	
Holding breath (HB)	31	16	9	28	18	10	10	5	6	5	1	16	8	**31**
Matrix of co-occurrences of pain behaviors in case group (n = 124), %														
Tense face (TF)	**100**													
Grimace (G)	40	**40**												
Fearful look (FL)	33	12	**33**											
Closing eyes (CE)	80	40	23	**80**										
Raising upper lip (RL)	57	31	16	52	**57**									
Moving body part (MB)	30	16	10	27	18	**30**								
Panicky (P)	29	12	12	23	15	16	**29**							
Not cooperating (NC)	14	9	7	11	9	7	7	**14**						
Seeeking comfort (SC)	20	6	11	16	9	7	8	3	**20**					
Aggression (A)	17	11	7	15	10	13	11	7	2	**17**				
Crying (C)	2	1	0	2	2	0	0	0	0	0	**2**			
Moaning/groaning (M)	44	17	16	36	26	15	19	8	8	9	2	**44**		
Sounds/verbal (S)	23	10	6	21	15	11	12	4	7	8	1	11	**23**	
Holding breath (HB)	32	18	11	27	20	11	12	7	7	7	1	19	8	**32**
Matrix of co-occurrences of pain behaviors in control group (n = 50), %														
Tense face (TF)	**100**													
Grimace (G)	40	**40**												
Fearful look (FL)	22	8	**22**											
Closing eyes (CE)	78	40	14	**78**										
Raising upper lip (RL)	60	38	12	56	**60**									
Moving body part (MB)	22	10	4	20	12	**22**								
Panicky (P)	10	2	4	8	4	6	**10**							
Not cooperating (NC)	4	4	0	4	4	0	2	**4**						
Seeeking comfort (SC)	16	6	6	14	8	6	2	0	**16**					
Aggression (A)	2	0	0	2	0	2	0	0	2	**2**				
Crying (C)	0	0	0	0	0	0	0	0	0	0	**0**			
Moaning/groaning (M)	20	10	2	20	12	8	2	2	4	0	0	**20**		
Sounds/verbal (S)	10	2	4	8	8	4	4	0	0	0	0	0	**10**	
Holding breath (HB)	30	12	4	28	14	10	4	0	4	0	0	8	6	**30**

The main diagonals with the bold figures present the prevalence of the pertinent items

Table 3 Logistic regression analysis on scores of painful activities with case/control group as criterion variable and pain behaviors as independent variables

	OR [1]	***P***	**95% CI**
			low - up
Tense face [2]	-	-	-
Grimace	1.05	0.88	0.53 to 2.08
Frightened/fearful look	1.71	0.17	0.79 to 3.72
Eyes (almost) squeezed	1.21	0.65	0.53 to 2.73
Raising upper lip	0.94	0.87	0.48 to 0.186
Moving body part	1.56	0.27	0.71 to 3.41
Panicky, panics attack	**3.67**	**0.01**	**1.34 to 10.08**
Not cooperating	3.76	0.09	0.83 to 17.05
Seeking comfort	1.25	0.63	0.51 to 3.04
Aggression/anger	**11.73**	**0.02**	**1.51 to 91.06**
Moaning/groaning	**3.13**	**0.01**	**1.42 to 6.87**
Sounds of restlessness/verbal expressions	2.53	0.08	0.91 to 7.07
Holding breath/faltering respiration	1.11	0.77	0.54 to 2.31

[1] Figures in bold signify significant odds ratios; [2] item is continuously present, and could therefore not be executed in this analysis
Abbreviations: OR=odds ratio; CI = Confidence Interval

Both interrater agreement (ICC = 0.92) and intrarater agreements of the two researchers (ICC = 0.96 and 0.90) were good. The Kuder Richardson coefficient was 0.49, which indicates moderate internal consistency.

Table 4 Dimensional loadings of the REPOS items

	Quantification (z-score)
Tense face	1.44
Eyes (almost) squeezed	1.14
Raising upper lip	0.84
Grimace	0.23
Moaning/groaning	-0.08
Holding breath/faltering respiration	-0.18
Moving body part	-0.35
Sounds of restlessness/verbal expressions	-0.39
Not cooperating	-0.45
Panicky, panics attack	-0.46
Aggression/anger	-0.46
Seeking comfort	-0.59
Frightened/fearful look	-0.69

For 159 residents (91%) nurses' pain ratings were available, for both an activity and a rest situation. In the control group (n = 50), pain self-report was available for 49 residents (98%) during painful activity and for 48 residents (96%) at rest. REPOS and NRS-resident had a correlation of r_s = 0.01; (95% CI:-0.27 to 0.29) for the activities and a correlation of 0.40 (95% CI:0.14 to 0.61) for the rest situations. Correlations between REPOS and NRS-nurse were small to medium (r_s = -0.12 to 0.36); correlations between REPOS and PAINAD were large (r_s = 0.61 to 0.75) (Table 5).

Median REPOS activity score was 5 (IQR 3 to 6) and 4 (IQR 3 to 5) for respectively case group and control group. Median REPOS rest score was 1 for both groups. The two-way ANOVA showed that REPOS score for the case group was significantly higher than for the control group (F = 10.1; df 1,169; *P* = 0.002). In terms of sensitivity to change, significant differences were found between activity scores and rest scores (F = 280.1; df 1,170; *P* = 0.00). No interaction effect between groups (case and control) and condition (activity and rest) (F = 0.01; df 1,170; *P* = 0.95) was found. Overall, scores for residents with vascular dementia were higher than those for residents with Alzheimer, but did not differ significantly. Only for one item, eyes (almost) squeezed, a trend in terms of a difference was found (*P* = 0.10). This behavior was seen in all but one of the 23 residents with vascular dementia (96%) during an activity. It was seen in 18 of the 24 residents with Alzheimer's disease (75%).

Cut-off scores

For the whole sample REPOS score 3 had the highest differential qualities with a good sensitivity (0.85) and specificity (0.83). Sensitivity was 0.86 and 0.82, and specificity 0.78 and 0.96 for case and control group, respectively. This would seem to indicate that the same cut-off score is applicable for each group.

Table 5 Spearman Rank correlations between REPOS and other pain scales

	Case group r_s (95% CI)	**Control group r_s (95% CI)**
REPOS during painful activity		
NRS-resident	-	0.01 (-0.27 to 0.29)
NRS-nurse	0.19 (0.01 to 0.35)	0.36 (0.09 to 0.58)
PAINAD	0.75 (0.66 to 0.82)	0.61 (0.40 to 0.76)
REPOS at rest		
NRS-resident rest	-	0.40 (0.14 to 0.61)
NRS-nurse	-0.12 (-0.29 to 0.06)	0.20 (-0.08 to 0.45)
PAINAD	0.64 (0.52 to 0.73)	0.66 (0.46 to 0.80)

Abbreviations: CI = Confidence Interval; REPOS = Rotterdam Elderly Pain Observation Scale; NRS = Numeric Rating Scale; PAINAD = Pain Assessment in Advanced Dementia

DISCUSSION

In the present study we explored pain behavior in nursing home residents of various cognitive levels, from cognitively intact to severely cognitively impaired. The 10-item REPOS showed good concurrent validity with PAINAD. The correlations with resident's self-report and nurse's NRS were disappointingly low.

We restricted the population to residents with chronic pain, defined as pain intensity of four or higher in the preceding weeks as judged by caregiving nurses. The clinical diagnoses indeed provide further evidence of chronic pain.

Since the gold standard of pain assessment, self-report, cannot be achieved in non-communicating older adults, observing pain behavior during activities may be the only alternative. Chronic pain implies that residents may have pain with the slightest movement, and for that reason, we observed residents when being washed or being dressed.

Proximity scaling did not yield a substantial difference between case and control group, which justified inclusion of all residents in our model. The resulting one-dimensional model showed a good fit. This model allows summing up items into a total score. Furthermore, we found it was justified to dichotomize the REPOS response categories. An additional benefit is meeting the desirability of pain scales being as user-friendly as possible.

Our findings show low internal consistency of the 10 items, which might partly be explained by the overall low prevalences and co-occurrences of the behaviors. The relatively low prevalences of behaviors found during activities are in line with other studies concluding that older adults show fewer and weaker responses to pain.[20,21] So do older adults with cognitive impairment in particular, as they have limited ability to express themselves; personal and sociocultural factors might then be of relevance. Nevertheless, a significant difference was found for REPOS scores between case and control group, but on item-level only two of the ten items were significantly more frequent in the case group, namely panicky, panics attack and moaning/groaning. A comparable study found higher scores for facial expressions and guarded behavior in cognitively impaired patients compared with cognitively intact patients.[8]

Correlations between REPOS and NRS-resident and NRS-nurse were low, yet comparable to those of previous studies.[8,20,22,23] A possible explanation why the elderly would underreport pain is reluctance to complain, a tendency to resist (too much) medication, or simply being convinced that pain is normal in later life.[1] In addition, sufferers of chronic pain may tend to avoid painful procedures and are accustomed to pain always being present. This could explain why they typically underestimate pain when being asked. Nurses or nursing assistants are known to

underestimate pain in many different settings.[24] This may be even more so in nursing home settings, because there is considerable understaffing. It is difficult to even fulfill basic care and this may result in an unwanted neglect of pain and pain treatment. Furthermore, nursing assistants usually are hardly educated on pain management. Future studies need to evaluate REPOS, self-report and nurse's report in different settings, e.g. postoperatively in hospital or during physiotherapy, in the same type of study group. This would show whether the low correlations are consistent in other settings and/or situations as well.

We did find large correlations between REPOS and PAINAD. Overall, our validity estimates, varying from small to large, were not unequivocal. Being aware that nurses tend to underreport pain intensity, we feel confident that the congruent validity of REPOS is adequate.

We compared pain behavior between 24 residents with Alzheimer's disease and 23 residents with vascular dementia, but scores on none of the behaviors differed significantly between these groups. Our samples of the two types of dementia are small, which could be explained by the fact that the diagnosis of dementia is often unknown. Nursing homes residents do not routinely undergo CT-scans to diagnose the type of dementia. Therefore, dementia may remain unrevealed, or residents may have combined types of dementia, as often was seen in our study. In a review study, Scherder et al. (2005) reported different functioning of pain-related brain areas among various dementia groups, suggesting possible differences in pain experiences.[25] For example, Alzheimer patients report less pain intensity and pain affect than non-demented people, and patients with vascular dementia tend to demonstrate more intense pain behavior than controls do. We would need larger sample sizes to further explore these differences and their effects on daily pain treatment.

We found REPOS scores of three and higher to be indicative of (chronic) pain. The cut-off of three seems somewhat low, but also subtle facial activities and a limited number of behaviors could suffice to indicate pain. Additionally, scores of three or higher could also result from other emotional states, like anger or sadness, without pain. We, therefore, provide a decision tree that asks caregivers to reflect on the significance of the score obtained, and act in accordance with what they conclude. Our results suggest that the cut-off score of three might be useful for nursing home residents with any level of cognitive function. Nevertheless, further research is needed in larger populations in order to substantiate this supposition.

Strengths and weaknesses of the study

We did not include assessments before and after administration of analgesics and we did not document time since last administered analgesic. We chose a similar activity (being washed or dressed) for all residents because we believe this type of

activity exacerbates the chronic pain always lurking in the background. We realize, however, that this choice is based on experience only and not scientifically based.

The fact that NRS ratings were based on a larger period of time, namely the whole activity, and the observed behaviors on two minutes of this activity is a methodological weakness that can be held responsible for the small correlations.

A major advantage of our study is the fact that it was performed in six different nursing homes improving the external validity of the findings.

CONCLUSIONS

In conclusion, REPOS appears to be promising for identifying pain in a broad range of nursing homes residents. This is one of the first studies evaluating possible differences in pain behavior between types of dementia. To improve pain management, we determined a cut-off score indicating pain and provide a step-by-step decision tree. As the scale is concise, we expect good usefulness in daily practice, provided that caregivers are adequately instructed. In a next phase, we will perform a pilot implementation of REPOS.

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7

Are pain and pain treatment in nursing home residents related to cognitive level?

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Submitted

ABSTRACT

Background
Pain and the quality of pain treatment has been scarcely studied in non-verbal older adults, other than with dementia.

Objective
To evaluate the relation between pain and pain treatment in nursing home residents with varying cognitive levels.

Study population
Dutch nursing home residents with pain, categorized into three groups based on MMSE.

Methods
Sociodemographic, medical information and cognitive level (MMSE) were collected. Pain during a painful situation was assessed with the Rotterdam Elderly Pain Observation Scale (REPOS), and pain in the previous week with Doloplus-2, and Numerical Rating Scale (NRS), either by residents themselves or nurses.

Results
Of 172 residents, 67 were non-verbal, 55 were moderately to severely cognitively impaired, and 50 were mildly impaired or cognitively intact. Pain according to the REPOS was significantly different for the three groups (p=0.04); the mildly impaired and cognitively intact residents scored lowest. Proportion of residents for who no analgesics were prescribed was highest in non-verbal group (p=0.001). Three quarters of non-verbal residents received one or more non-pharmacological interventions versus half of the residents in other groups (p=0.01). The Pain Management Index (PMI) scores using NRS showed inadequate pain treatment varying between 59% and 69%. PMI scores according to REPOS were 71%, 75%, and 43%, respectively.

Conclusions
Non-verbal residents in pain received significantly less analgesics than cognitively impaired and intact residents resulting in more inadequately treated residents. Nurses need to be trained in assessing and treating pain in nursing home residents according to a valid behavioral scale.

INTRODUCTION

Pain treatment should be tailored to different types and intensities of pain. To determine whether pain treatment is really appropriate and effective we need accurate methods of pain assessment.

From international studies it appeared that about a quarter of community-dwelling elderly and nursing home residents in pain did not receive any pain medication. Moreover, those with cognitive impairment received significantly fewer analgesics, both in number and dosage, than those without cognitive impairment.[1-3] Smalbrugge et al. even found that almost half of cognitively intact to mildly impaired nursing home residents in pain did not receive analgesics.[4] Studies comparing a broader range of cognitive levels reported a significantly higher amount of analgesics in cognitively intact persons than in persons with severe impairment, both in hospitalized older adults[5] and nursing home residents.[6] In addition, Shega et al. used the Pain Management Index (PMI) to evaluate adequacy of prescribed analgesics in community-dwelling patients with dementia. Inadequate pain treatment was found in 46%, and those with lowest cognitive level had three times higher chance of insufficient analgesics.[7]

In most studies self-report is used to assess pain. Overall, low failure rates by older adults with varying cognitive impairments using different self-report scales to measure their pain are reported. Unfortunately, consistency in scores between some of these scales and failure rates are poor for severely cognitively impaired patients.[8-10] Therefore, a standardized and valid observation scale is needed to measure pain in these patients. Studies in which pain observation scales are described in combination with pain treatment are scarce, and data on non-verbal older adults other than with dementia are notably lacking.

The present study focused on a multicenter nursing home population with pain, distinguished by cognitive level, and including a large non-verbal group. We aimed to answer the following research questions:

- What is resident's pain according to several methods?
- How are they treated for their pain?
- To what extent is cognitive level related to resident's pain treatment?
- How do nurses evaluate resident's pain treatment?

METHODS

Design

This cross-sectional study is part of a larger pain study in constructing and validating the Rotterdam Elderly Pain Observation Scale (REPOS). Data were

collected in six nursing homes from 2003 up to and including 2005. The Erasmus MC Medical Ethical Review Board approved the study, and so did directors and client boards of the nursing homes.

Participants

One hundred seventy-four residents of somatic, rehabilitation and psychogeriatric wards in six Dutch nursing homes, all located in Rotterdam and surroundings. Residents were included if they were in pain according to a staff nurse or by the residents themselves. Pain was defined as having a mean pain intensity of four or higher on the Numeric Rating Scale (NRS), which can be related to loss of function.[11]

Either residents themselves or legal representatives gave informed written consent.

Classifications and measurements

Demographics and medical data were extracted from medical charts.

We classified residents' most painful diagnoses conform the International Classification of Diseases (ICD-10, 1994). For example, post-stroke pain was classified under 'diseases of the circulatory system', severe decubitus under 'diseases of the skin and subcutaneous tissue' and pain caused primarily by arthritis under 'diseases of the musculoskeletal system and connective tissue'. In addition, residents were classified by the cause of their communication problem, such as dementia, aphasia, end-stage of life and sub-comatose status due to severe brain damage.

Cognitive status was determined by means of the Mini Mental State Examination (MMSE). This valid and reliable measure consists of 11 items, yielding a total score ranging between 0 and 30. Scores 0 to 9 indicate severe cognitive impairment, 10 to 17 moderate cognitive impairment, 18 to 23 mild cognitive impairment, and 24 to 30 no cognitive impairment.[12] Completion takes 5 to 10 minutes. In the present study, MMSE was used to stratify residents into three main groups. The first group included residents who could not verbally communicate at all, as shown from inability to answer one single question of the MMSE. The second group comprised the moderately and severely cognitively impaired, and the third group the mildly cognitively impaired and cognitively intact residents.

Performance status was determined by the Karnofsky index, with scores ranging from 0, representing deceased, to 100, representing normal situation without complaints or diseases.[13]

Pain measurements

The Rotterdam Elderly Pain Observation Scale (REPOS) has been validated to measure pain in nursing home residents with varying cognitive levels (Van Herk et al., submitted). Inter- and intrarater reliability were good, and internal consistency was moderate. Significant differences were found between painful and rest situations, and a large correlation was found with PAINAD ($r = 0.75$), indicating

good validity. The REPOS consists of ten behaviors (relating to facial expression, emotional status, motor behavior, and vocalization), which are scored on absence (= 0) or presence (= 1) after a two-minute observation period, with a possible total score ranging from 0 to 10. Both sensitivity (0.85) and specificity (0.83) were optimal with a cut-off score of 3. REPOS scores of 3 and higher indicate pain.

The Doloplus-2 scale is a behavioral pain assessment scale for elderly with verbal communication disorders. It consists of ten items divided into three subscales; somatic scale comprises 5 items, psychomotor scale 2 items, and psychosocial scale 3 items. Each item is scored using four exclusive and progressive levels (0 to 3), yielding a total score from 0 to 30. Total scores of 5 or higher, indicate the presence of pain.[14] The scale was found reliable and valid to assess pain in patients with communication problems.[15] In the current study, the Doloplus-2 was completed for the resident's pain in the previous week by the nurse who was most familiar with the resident.

The Numeric Rating Scale (NRS) rates pain intensity from 0 ('no pain') to 10 ('worst possible pain'), and was found a reliable and valid pain assessment in older adults with varying cognitive levels.[8] Nurses and the mildly cognitively impaired and intact residents in group 3 were asked to rate pain intensity for previous week.

Pain treatment

Pain medication was evaluated by means of pharmacological and non-pharmacological pain treatment. Both routine and as needed analgesics, up to a maximum of four per resident, were classified according to the World Health Organization (WHO) analgesic ladder. Step 1 consists of acetaminophen and NSAIDs, step 2 of weak opioids (e.g. tramadol) and step 3 of strong opioids (e.g. morphine).[16,17]

Co-analgesics (adjuvants) were classified into three categories: antidepressants, anti-epileptics (e.g. gabapentine), and anxiolytics/hypnosedatives (e.g. benzodiazepines). Co-analgesics were recorded up to a maximum of 3 per resident.

The Pain Management Index (PMI) was used to evaluate adequacy of analgesics. The index compares the analgesic prescribed with the level of pain intensity. To construct the index, the level of pain intensity is categorized as 0 (no pain), 1 (1 to 3: mild pain), 2 (4 to 7: moderate pain), and 3 (8 to 10: severe pain). For pain intensity, residents' self-report and nurse ratings by means of NRS, and REPOS were used. The pain level was subtracted from the highest level of prescribed analgesics according to the WHO ladder, scored as 0 (no analgesics), 1 (step 1), 2 (step 2), and 3 (step 3). PMI scores can range from -3 (a resident with severe pain and no analgesics) to 3 (a resident without pain and receiving analgesics from step 3). These scores are then dichotomized: negative scores indicate inadequate pain treatment, and scores from 0 to 3 are considered indicative of acceptable pain treatment.[18]

Procedure

Staff nurses were asked to identify those residents who were in pain in the previous week (NRS ≥ 4). After written informed consent, each resident was videotaped during a possibly painful care activity (washing or dressing). A two-minutes episode of each recording was observed and scored with REPOS. On the day of recording, a nurse completed the Doloplus-2 to assess residents' pain in the previous week and the Karnofsky index to assess residents' performance status. In addition, both the resident's nurses and the residents (if possible) rated the pain intensity in the previous week. Furthermore, nurses were asked whether they were satisfied with the prescribed analgesics ('not at all, a little, fairly or completely), and which non-pharmacological pain relieving interventions they used per resident using the following 6 answer categories: 'no intervention', 'change in posture', 'massage', 'music/other relaxation', 'heat/cold', and 'other'.
Resident's cognitive status was determined by the researcher using MMSE.

Statistical analyses

Data analysis was performed with SPSS 14.0. Mean and standard deviations (sd) were used for normally distributed variables; median and inter quartile ranges (IQR) for not normally distributed variables.

Associations between the three groups were tested with the one-way ANOVA test on normally distributed variables. To compare the pain scores between two groups the Post Hoc Bonferroni test was applied. For not normally distributed variables the Kruskal-Wallis Test was applied, and for continuous data the Chi-square test.
A *P*-value of 0.05 (two-tailed) was considered statistically significant.

RESULTS

Demographics

In total, 174 residents were included in the study. The MMSE was missing for two residents. The remaining 172 residents were divided into three groups based on their cognitive/communication level (Figure 1). Group 1 comprised non-communicative residents (n = 67) who were not able to complete any item of the MMSE for several reasons: severe dementia (57%), severe aphasia (24%), acquired brain injury (sub comatose status) (6%), terminally ill (sedated) (7%), and no command of the Dutch language (6%). The second group, the moderately to severely impaired (n = 55), had a mean MMSE-score of 9.2 (sd 5.4). The communication difficulties of these residents were due to cognitive impairment (82%) and aphasia (18%). Group 3 comprised 50 cognitively intact and mildly impaired residents with a MMSE-score of 18 and higher, with a mean of 23.7 (sd 4.0). Detailed sociodemographic and medical variables are presented in Table 1.

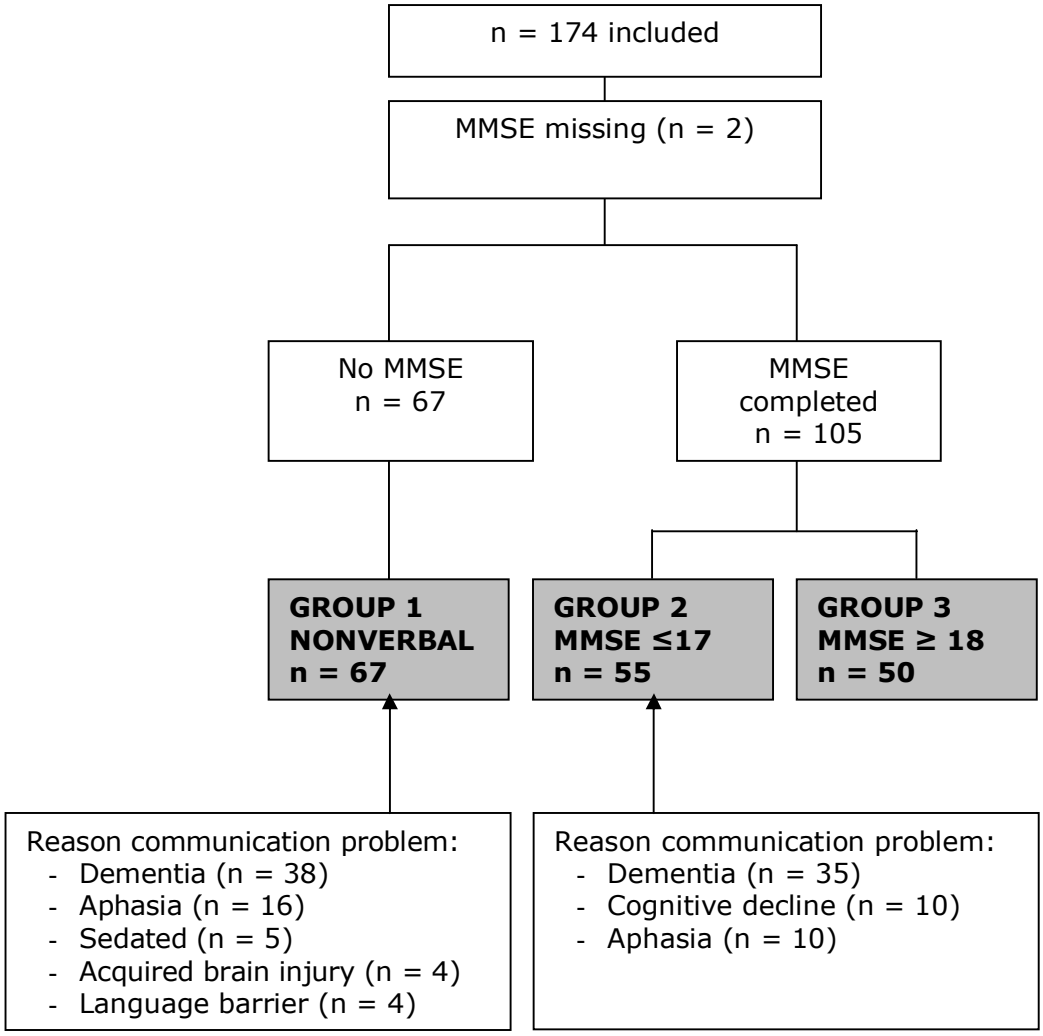

Figure 1 *Inclusion flowchart*

Pain characteristics

Table 2 show pain intensities according to REPOS, Doloplus-2, and NRS. Mean REPOS-scores were respectively 4.7 (sd 1.8), 4.8 (sd 1.9), and 3.9 (sd 1.6), and differed significantly (P = 0.04). The non-verbal residents had highest Doloplus-2 mean score of 9.0 (sd 5.8), but total scores did not differ significantly and clinically between the groups.

The intact to mildly impaired residents rated their pain intensity in the previous week with a mean NRS of 6.2 (sd 1.8). Of the moderately to severely impaired residents, only 18 self-report ratings were collected with a mean of 6.8 (sd 1.9).

The pain ratings of nurses were similar across the three groups.
Comparing the groups separately according to each pain scale, there was a trend that non-verbal and moderately to severely impaired residents differed from the mildly impaired and cognitively intact group on REPOS, respectively P = 0.08 and P = 0.07.

Table 1 Sociodemographic and medical variables (n = 172)

	Group 1 non-verbal	**Group 2 moderate to severe**	**Group 3 intact to mild**	**Total group**
n	67	55	50	172
Gender (females)[1] n (%)	51 (76)	32 (58)	26 (52)	109 (63)
Median age in yrs[1] (IQR)	82 (72 to 88)	84 (76 to 89)	78 (70 to 84)	82 (72 to 87)
Mean MMSE[1] (sd)	-	9.2 (5.4)	23.7 (4.0)	16.1 (8.6)
Median Karnofsky score[1] (IQR)	40 (40 to 50)	50 (50 to 60)	60 (50 to 60)	50 (40 to 60)
Nursing home residents n (%)				
NH 1	19 (28)	20 (36)	23 (46)	62 (36)
NH 2	13 (19)	4 (7)	8 (16)	25 (15)
NH 3	14 (21)	7 (13)	12 (24)	33 (19)
NH 4	4 (6)	3 (5)	7 (14)	14 (8)
NH 5	14 (21)	18 (33)	-	32 (18)
NH 6	3 (5)	3 (6)	-	6 (4)
Most painful diagnosis according to ICD-10 n (%)				
Diseases of the musculoskeletal system and connective tissue	27 (40)	24 (44)	23 (46)	74 (43)
Diseases of the circulatory system	14 (21)	16 (29)	15 (30)	45 (26)
Diseases of the skin and subcutaneous tissue	11 (16)	7 (13)	3 (6)	21 (12)
Diseases of the nervous system	4 (6)	2 (3)	5 (10)	11 (6)
Injury, poisoning and certain other consequences of external causes	5 (8)	2 (3)	2 (4)	9 (5)
Neoplasms	2 (3)	1 (2)	-	3 (2)
External causes of morbidity and mortality	3 (4)	-	1 (2)	4 (3)
Diseases of the digestive system	-	1 (2)	1 (2)	2 (1)
Diseases of the genitourinary system	1 (2)	1 (2)	-	2 (1)
Could not be classified	-	1 (2)	-	1 (1)
Number of comorbidities[2]				
None	3 (4)	1 (2)	2 (4)	6 (3)
One	20 (30)	11 (20)	14 (28)	45 (26)
Two	33 (50)	21 (38)	21 (42)	75 (44)
Three (or more)	11 (16)	22 (40)	13 (26)	46 (27)

[1] Signifcant differences between three groups (P = 0.000 to 0.03); [2] Up to a maximum of three comorbidities were reported
Abbreviations: IQR = inter quartile range; MMSE = Mini Mental State Examination; sd = standard deviation; NH = nursing home

Table 2 Scores according to pain scales

Pain scale	Group 1 non-verbal	Group 2 moderate-severe	Group 3 intact-mild	Total group	*P*
REPOS	n = 67	n = 55	n = 50	n = 172	
Mean (sd)	4.7 (1.8)	4.8 (1.9)	3.9 (1.6)	4.5 (1.8)	0.04[1]
Median (IQR)	5.0 (3 to 6)	5.0 (4 to 6)	4.0 (3 to 5)	5.0 (3 to 6)	
Doloplus-2	n = 65	n = 54	n = 50	n = 169	
Mean (sd)	9.0 (5.8)	7.2 (4.2)	7.4 (4.6)	7.9 (5.0)	0.10[1]
Median (IQR)	8.0 (4 to 13)	7.0 (4 to 10)	7.0 (4 to 10)	7.0 (4 to 11)	
NRS nurse	n = 65	n = 53	n = 49	n = 167	
Mean (sd)	5.0 (2.7)	5.2 (2.4)	5.4 (2.1)	5.2 (2.4)	0.94[2]
Median (IQR)	6.0 (4 to 7)	6.0 (4 to 7)	6.0 (4 to 7)	6.0 (4 to 7)	
NRS self-report	-	n = 18	n = 49	n = 68	
Mean (sd)	-	6.8 (1.9)	6.2 (1.8)	6.4 (1.8)	0.26[3]
Median (IQR)	-	6.5 (6 to 8)	6.0 (5 to 7)	6.0 (5 to 7)	

[1] ANOVA-test; [2] Kruskall Wallis test; [3] Mann-Whitney test
Abbreviations: sd = standard deviation; IQR = Inter Quartile Range; REPOS = Rotterdam Elderly Pain Observation Scale

Pain treatment

Twenty-nine per cent of residents in non-verbal group received no analgesics at all, versus 20% and 10% in the other groups, respectively. Routinely administered analgesics, including all steps, were prescribed in fewer residents from the non-verbal group (55%) compared to the moderate-severe group (67%), and the intact group (72%). Proportions of residents prescribing 'as needed' analgesics were comparable for the three groups (Table 3). Overall, proportions of residents prescribed any analgesics, either routine or as needed, versus none differed significantly between the groups ($P = 0.02$).

Acetaminophen was the most frequently prescribed 'as needed' analgesic. Daily dosages of routinely administered acetaminophen did not differ significantly between the groups, with a median daily dosage of 2000 mg for group 1, and 3000 mg for both other groups ($P = 0.19$).

Residents who were treated inadequately according to pain ratings of nurses, ranged from 59% to 66%. According to residents' self-report, 67% to 69% received inadequate pain treatment. Based on REPOS, PMI scores were found inadequate in 71%, 75%, and 43%, respectively (Table 4). The PMI scores based on REPOS differed significantly between group 1 and 3 ($P = 0.04$) and group 2 and 3 ($P = 0.01$).

For all groups the most frequently prescribed co-analgesics were anxiolytics/ hypnosedatives, ranging from 35 to 56% (Table 3).

Table 3 Prescribed analgesics according to WHO ladder in n (%) per group (n = 172)

Highest prescribed (co)analgesics	Group 1 non-verbal n (%)	Group 2 moderate/severe n (%)	Group 3 intact/mild n (%)	Total group n (%)
None	19 (29)	11 (20)	5 (10)	35 (20)
Step 1 routine	23 (34)	30 (54)	24 (48)	77 (45)
Step 2 routine	3 (5)	7 (13)	6 (12)	16 (9)
Step 3 routine	11 (16)	-	6 (12)	17 (10)
Step 1 as needed	10 (15)	7 (13)	7 (14)	24 (14)
Step 2 as needed	0	0	0	0
Step 3 as needed	1 (1)	0	2 (4)	3 (2)
Anxiolytics/hypnosedatives[1]	23 (35)	31 (56)	28 (55)	82 (48)
Antidepressants	8 (12)	4 (7)	13 (25)	25 (15)
Anti-epileptics	9 (14)	4 (7)	5 (10)	18 (9)

[1] *number of residents receiving one or more anxiolytics/hypnosedatives*

Caregiving nurses reported one or more non-pharmacological interventions in 74% of the residents in group 1, and about half of the residents in groups 2 and 3 (P = 0.01). The most frequent non-pharmacological intervention in all groups was change in posture (resp. 56%, 44%, 29%), followed by massage (resp. 20%, 6%, 14%).

Seventy-five per cent of interviewed nurses were satisfied with the prescribed analgesics for the total study population. Twenty-six per cent were not or just a little satisfied with the prescribed pain medication in the non-verbal group compared to respectively 13% and 17% for both other groups (P = 0.20).

Table 4 Inadequate treatment according to Pain Management Index (PMI) in %

Pain scale	Group 1 non-verbal	Group 2 moderate/severe	Group 3 intact/mild	Total Group	P^1
NRS self-report	-	67	69	68	0.60
NRS nurse	59	66	59	61	0.29
REPOS	71	75	43	64	0.04

[1] *ANOVA-test*
Abbreviations: NRS = Numeric Rating Scale; REPOS = Rotterdam Elderly Pain Observation Scale

DISCUSSION

In this multicenter study, pain and pain treatment were compared between nursing home residents with varying cognitive levels. Our aims were to assess pain during a painful situation and during a week, using observational scales, self-report and nurse ratings, and to compare pain levels and prescribed pain analgesics. REPOS was the only scale that showed significant differences between the groups, indicating the relevance of measuring pain during a painful situation, especially in non-verbal residents and those with higher cognitive impairments. Results showed that non-verbal residents received significantly less analgesics than the other groups. This is in accordance to previous studies.[3,4,6]

Although differences in pain medication among the groups were found, 64% of the total population received analgesics on a routine basis, which is much more than the 30% and 47% found in a comparable foreign study population.[3,19] The most frequently prescribed drug in all groups was acetaminophen, which is in line with findings from other studies.[4,20] Though in our study the daily dosage of acetaminophen was lower in non-verbal residents than the other groups, it did not differ significantly. Yet, Horgas and Tsai, and Pickering and colleagues found a significant lower dosage of acetaminophen in patients with than without a cognitive disorder.[1,21] Horgas and Tsai (1998) included a nursing home population with similar diagnoses and varying cognitive levels. The difference with our study is that they did not describe a painful condition in one-third of their population, and we only included residents with pain. Pickering et al. (2006) compared administered analgesics between Alzheimer patients and cognitively intact nursing home residents. They made a difference in analgesics given for chronic pain and acute pain, and found only a significant difference between the groups for chronic pain, for who Alzheimer patients received a significantly lower dosage. Although our study population was mainly diagnosed a chronic painful condition, the non-verbal and severely cognitively impaired residents in our study not only comprised Alzheimer patients.

Smalbrugge et al. showed a significant difference in the prescription of anxiolytics/hypnosedatives between residents with and without pain, indicating the relevance of these co-analgesics.[4] Our study showed similar percentages of the different co-analgesics among the groups compared to the group with pain in the study of Smalbrugge, except for antidepressants, which were more prescribed in cognitively intact residents.

Frequency of non-pharmacological interventions was highest for the non-verbal residents, for whom nurses were least satisfied with the prescribed analgesics. This suggests that nurses are aware of pain in these residents, and are willing to improve their conditions, but probably need a more objective way of measuring pain to lean on.

According to the WHO ladder, the more severe pain, the higher the pain treatment should be. Overall, only 13% of residents were prescribed strong opioids. Although self-report is the golden standard to assess pain intensity, it is not always possible in moderately to severely cognitively impaired residents.[8,22] In these residents, observation or estimation of residents' pain is the only alternative. Overall, high and similar percentages of inadequate pain management were found in all groups, which were somewhat higher than the number found in a study in community-dwelling elderly with dementia.[7] Shega et al. demonstrated that almost half their study population were treated insufficiently, and the higher the cognitive impairment, the more chance of inadequate pain treatment. The difference with our study is that we included residents with a painful condition on forehand, suggesting more residents with pain.

While no differences were found in adequacy of pain treatment when pain was evaluated by means of self-report and nurses' report, PMI scores based on REPOS, however, demonstrated higher inadequacy of pain treatment in non-verbal and cognitively impaired residents compared to residents who were able to report pain themselves. Knowing nurses are not always a reliable source in assessing pain,[23-25] the use of a pain observation scale seems to have an additional value to determine effective pain management, at least during a caring activity.

Hutt et al. (2006) developed the Pain Medication Appropriateness Scale (PMAS) to determine the adequacy of pain treatment in nursing homes more extensively. Unlike the PMI, this scale reckons with different types of pain and pain treatments, including adjuvants, and the actual relief for patients.[26]

Limitations of this study

Questions could be raised about robustness of the behavioral pain scales used. Previous studies with Doloplus-2 show moderate psychometric qualities, specifically for the psychosocial category.[27,28] REPOS was developed and validated based on the data of this study population.

More research is needed to establish the validity of the PMI based on REPOS, because it is not yet demonstrated that higher REPOS scores indicate more pain. Therefore, these results should be interpreted with caution.

This also counts for our findings on co-analgesics, because some drugs such as antidepressants and anti-epileptics are prescribed for neuropathic pain but also to treat depression and convulsions respectively. Our study design did not provide for recording details on diagnostic reasons for prescription.

Recommendations

The findings of our study emphasize that the use of a scale that asks nurses to observe specific pain behaviors more directly deserves a major role in daily clinical care, especially, in non-verbal and severely cognitively impaired residents. Nurses

and other caring disciplines should learn to use other ways of pain assessment, and should be familiar with the pain medication they administer to their residents.

Although guidelines about treatment and of the most common chronic pain conditions are available,[29,30] more evidence-based research is seriously needed to explore the inadequacy of pain treatment and clinical effects. A recent study did a good attempt already, by comparing different pain scales in relation to a treatment protocol in nursing home residents with (severe) dementia.[31] The Verbal Descriptor Scale (VDS) as self-report and the two informant ratings' scales, Pain Assessment for the Demented Elderly (PADE) and Pain Assessment in Noncommunicative Elderly persons (PAINE), were most promising scales in a group with pain at baseline. This group showed a significantly higher decrease in pain scores after standardized treatment than did comparison groups. Unfortunately, the authors established cut-off scores for pain themselves, as these are lacking in the literature. To determine valid cut-off scores for pain, behavioral pain scores could be related to functional status.[11] Apart from pharmacological treatment, nurses and physicians should also pay more attention to non-pharmacological interventions.[32] According to Kemp et al. prayers, regular exercise and heat/cold are helpful interventions.[20] Several of the participated homes were already doing a good job in using non-pharmacological interventions, whereas others would do well to expand their use and incorporate them in the standard treatment protocol.

In conclusion, our results indicate that non-verbal residents are at higher risk of less and more inadequate pain treatment than cognitively intact to severely impaired residents. Nurses need to be trained in assessing and treating pain in nursing home residents according to a valid behavioral scale.

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8

Evaluation of a pilot project for implementation of REPOS in daily practice

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ABSTRACT

Background
Pain assessment in elderly people with a communication disability is a well-known problem.

Objective
To explore the feasibility of a new pain observation scale.

Study group
Fifteen nurses employed at eight wards in one nursing home.

Methods
We developed the Rotterdam Elderly Pain Observation Scale (REPOS), which includes 10 behavioral items scored as present (1) or absent (0) after a 2-minutes observation. In addition, pain level is rated on the Numeric Rating Scale (NRS). A REPOS score of ≥ 3 in combination with a NRS of ≥ 4 indicates pain. Fifteen nurses received a 2-hours theoretical training, and performed paired bedside observations with the trainer. After obtaining a sufficient interrater agreement, nurses were asked to continue REPOS observations. These data were examined after six months.

Results
All nurses reached sufficient interrater agreement (kappa ≥ 0.61) within a median of 8 weeks (range 4 to 10), after a median of 12 observations. The next 6 months, in total 52 observations were completed by seven nurses at five different wards. Combined REPOS and NRS scores indicated pain in 22 (42%) of 52 observations. In most of these cases (77%) nurses took action as indicated in the decision tree that comes with the REPOS.

Conclusions
The REPOS is feasible in daily nursing practice provided training is given. The decision tree was a useful guide for nurses to reflect on residents' pain and take appropriate action.

INTRODUCTION

Standardized assessment of pain in daily practice is feasible, and can improve quality of life in patients with pain. Aiming to make pain management a standard priority in long-term care facilities, Weissman et al. (2000) reviewed fourteen specific indicators of pain management practice. These included facility of assessments tool for both cognitively intact and impaired residents, standardized documentation flow sheet, explicit education program for residents and families, etc. An education program was found to increase in the proportion of facilities (n = 87) having more than 51% of the target indicators from 14% to 74%.[1] Moreover, decreases in incidence and intensity of pain after monitoring pain by self-report have been found in hospitalized patients after surgery,[2] in cancer patients,[3] and in nursing home residents.[4] De Rond et al. (2001) implemented a pain registration program in a hospital setting, in which nurses needed to daily register self-reported pain intensity.[5] The implementation was found effective, as pain intensity decreased and quality of life improved. Similar results were found using the same pain registration method in Dutch nursing and residential homes.[6] In the latter study, about a quarter of the residents in somatic wards were not able to report their pain (intensity) due to cognitive impairments. Proportions of persons who cannot report pain themselves are higher at psychogeriatric wards. A standardized observation instrument could then be helpful to identify pain. Recently, the Rotterdam Elderly Pain Observation Scale (REPOS) has proven to be a valid instrument to measure pain in a nursing home population with communication problems (van Herk et al., submitted). The scale consists of ten behaviors, which are scored on absence (= 0) or presence (= 1) after two minutes observation. A decision tree is provided based on a cut-off score for pain to help nurses make a decision about treatment.

The present study describes the implementation process of REPOS to measure pain in nursing home residents who are unable to communicate their pain. As part of this process, nurses attended a theoretical and practical training program, aimed at mastering REPOS observations.

Our goal was to evaluate the feasibility of REPOS, by asking the following questions: what is needed to obtain satisfying interrater agreement and do nurses use REPOS in daily practice after the training?

METHODS

Design

This is an observational study conducted in one nursing home from January to December 2007. The Erasmus MC Medical Ethical Review Board approved the study, and so did the management of the nursing home involved.

Participants
Fifteen nurses from all wards were preselected to participate in our study. Type of wards were: psycho-geriatric (n = 1), somatic (n = 4), rehabilitation (n = 2), and one ward for residents with acquired brain injury. Before and apart from our study nurses had received an internal training about pain in general, and had been appointed as 'pain specialist' at their wards. Their median age was 42 years (range 21 and 60). They had a median of 15 years (range 1 to 31) working experience after getting their highest degree.
The trainer was a clinical nurse specialist with an expertise in pain in the elderly.

Instruments
REPOS was designed to measure pain in nursing home residents (van Herk et al., submitted). It consists of ten behaviors (relating to facial expression, emotional status, motor behavior, and vocalization), which are scored on absence (= 0) or presence (= 1) after a two-minute observation period, with a possible total score ranging from 0 to 10 (Appendix 1). An instruction chart with definitions of the ten items is available (Appendix 2). Inter- and intrarater reliability were good, and internal consistency was moderate. Significant differences were found between painful and rest situations, and a large correlation was found with PAINAD ($r = 0.75$), indicating good validity. Both sensitivity (0.85) and specificity (0.83) were optimal at a cut-off score of 3. REPOS scores of 3 and higher indicate pain, and requires intervention on the guidance of the step-by-step decision tree (Appendix 3). Part of the decision tree is the Numeric Rating Scale (NRS), in which 0 represents no pain and 10 represents the worst imaginable pain. Nurses need to rate the intensity of pain experienced during the two minutes of observation. NRS-scores of 4 and higher indicate substantial pain; such an intensity of pain has been shown to be related to loss of function.[7] The decision tree shows that pain is present and action is needed if REPOS score ≥ 3 in combination with NRS score ≥ 4.

Procedure
First, to determine trainer intrarater agreement, the trainer scored the behavior of 15 residents from videotape and repeated this after two weeks.

Nurses were personally invited, and participated in a skills training program aimed at mastering REPOS observations.

The training program consisted of a theoretical (2 hours) and a practical part. In the theoretical part, nurses were shown examples of all REPOS items, extracted from video-recordings of nursing home residents.

In the practical part, each nurse observed at least ten nursing home residents at the bedside together with the qualified trainer. Most observations were completed during a possibly painful situation, i.e. washing, wound care or physical therapy, because this was considered to be more educative. Directly after completing REPOS,

nurses evaluated the observations on the guidance of the decision tree. This asks nurses to consider whether it is really pain or perhaps another reason that causes a high REPOS score. Additionally, nurses rate pain also according to the Numerical Rating Scale (NRS), ranging between 0 (no pain) to 10 (worst pain).

After obtaining satisfactory agreement in practice, nurses were considered qualified to use REPOS independently and were instructed to continue scoring residents who could not verbally communicate their pain, and in whom pain was assumed, or whose pain medication had been adjusted. These data were collected for six months. During these months, the trainer visited the nurses once a week to support them and give feedback if necessary.

Statistical Analysis

To measure the interrater agreement at item level between the trainer and each of the participants Cohen's Kappa was determined. Kappa < 0.20 is considered poor, 0.21 – 0.40 fair, 0.41 – 0.60 moderate, 0.61 – 0.80 good, and 0.81 – 1.00 very good.[8] In this study, nurses reaching a kappa coefficient of 0.61 and higher were considered qualified to complete REPOS independently.

Intrarater and interrater agreement on total REPOS scores were measured by means of intraclass correlation (ICC) coefficient using the two-way mixed model.[9] ICC values below 0.40 were considered to reflect poor agreement, between 0.40 and 0.75 moderate to good, and above 0.75 indicate excellent agreement.[10]

RESULTS

Training phase

Intrarater agreement of the trainer was excellent (REPOS ICC = 0.98 and NRS ICC = 0.93).

In the practical part of the training program, 196 paired bedside observations were completed, 177 during a painful situation and 19 at rest. Twelve nurses (80%) needed one or two extra training sessions on the guidance of video observations. All nurses reached a sufficient Cohen's kappa (median 0.65; IQR 0.63 to 0.74) within a median of 8 weeks (range 4 to 10), after a median of 12 bedside observations (IQR 11 to 13).

Interrater agreements on total REPOS scores between trainer and participants were good and ICC coefficients ranged from 0.66 to 0.94, with a mean of 0.84. Interrater agreements for NRS were all higher than 0.71, with a mean of 0.87.

Interrater agreements at item level were good for five items, with kappa coefficients ranging from 0.63 to 0.74; the other five items showed agreements lower than 0.60 (Table 1).

Table 1 Interrater agreements coefficients on item level

Items	Cohen's kappa 196 paired observations
Grimace	0.74
Eyes (almost) squeezed	0.69
Raising upper lip	0.69
Holding breath/faltering respiration	0.66
Moving body part	0.63
Moaning/groaning	0.55
Frightened, fearful look	0.49
Tense face	0.46
Sounds of restlessness/verbal expressions	0.46
Panicky, panics attack	0.44

Use of REPOS in daily practice

After being qualified to use REPOS independently, seven nurses at five different wards completed 52 REPOS observations on 24 residents in a period of six months. Nine residents were observed more than once (2 to 9 times). For all observations median REPOS score was 4.0 (IQR 2.0 to 5.0), and median NRS 3.0 (IQR 2.0 to 5.0).

Combinations of a high REPOS score (≥ 3) and a high NRS score (≥ 4) were found in 22 of 52 observations (42%). In 17 of these 22 cases (77%) an action was reported: in 11 cases (65%) nurses informed either a physician or the staff nurse, in 5 cases (29%) either a pharmacological or non-pharmacological intervention was performed, and in 1 case (6%) a new observation with REPOS was scheduled.

DISCUSSION

Fifteen trained nurses were able to achieve sufficient interrater agreement within 4 to 10 weeks. Regrettably, the number of REPOS observations in the six months after training, however, were disappointingly low. Our results suggest that both bedside scoring and video scoring are useful to learn the REPOS. Either method has its advantages and disadvantages. Advantages of bedside scoring are the possibility for the observer to change position, and the observer being aware of the specific context. Observing a video has the advantage that all observers have the same view, and have the option to stop the tape, or watch the scene more than once. It is disadvantageous in that it does not provide contextual information.

Interrater agreement coefficients varied for the different REPOS items. This might be explained by low incidences of behaviors.[8]

Considering the high prevalence of chronic pain in nursing homes, and the overall undertreatment,[11-14] the actual number of REPOS observations performed after the training was disappointingly low. Several explanations might be proposed. For one, not all staff nurses or colleagues were convinced of the relevance of pain assessment. This attitude may have inhibited the trained nurses to perform observations. Another explanation is that wards may have been understaffed. Furthermore, in three wards all residents were able to communicate and therefore REPOS observations were superfluous. Literature reports also show that several barriers have to be overcome before a new instrument can be successfully embedded in daily practice.[15] On the other hand, facilitators for successful implementation are described as well. Simpson et al. reported implementation of a similar research-based nursing protocol among nursing home residents with dementia.[16] Following pertinent steps of this protocol and multidisciplinary collaboration were found to be the most important factors contributing to successful implementation. We believe that dedicated commitment from the management is relevant as well. A prerequisite for this commitment is early communication with the management of the nursing home about the implementation, and explaining the use of REPOS and the implementation process in a physicians' meeting. During the process we sustained discussions between nurses and physicians about high pain scores. In most cases nurses indeed reported high scores to the physician or staff nurse, which suggests this strategy had a positive effect.

Pain already has been designated as a quality indicator enforced by the Netherlands Health Care Inspectorate in 2007 in Dutch hospitals. Quality is expressed as the percentage of postoperative patients with adequate pain treatment (a pain intensity below 4). These results are made public and therefore this indicator might be a useful future facilitator for nursing homes as well. Quality indicators for nursing homes including decubitus and malnutrition are being applied. A recent report recommended other relevant indicators in nursing homes including pain.[17] Because self-report is not always possible, the implementation of REPOS can be helpful to comply with the quality indicator pain.

Limitations of the study

A possible limitation of this study is that it concerned only one nursing home. Moreover, we did not collected information about the total number of eligible residents during the six-months period. Such information would have given more insight into the feasibility of implementation at specific types of wards.

Finally, we failed to report the specific actions of physicians in response to high pain scores.

Future work

Based on the results of the current study a standardized protocol for the training of new nurses will be developed. REPOS will be implemented in other nursing homes

as well. In these new implementation studies the effects of non-pharmacological and pharmacological interventions based on high REPOS scores will be examined.

In addition, an instruction cd-rom, both in English and Dutch language, is being prepared. It will contain short video fragments of all REPOS-behaviors, several practice video fragments, and printable documents such as the manual, scoring lists, etc.

CONCLUSION

Using REPOS is feasible in daily nursing practice provided training is given. The route to successful pain treatment requires more than just pain assessment.

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9

Conclusions and general discussion

INTRODUCTION

Many international and national studies as well as other media reports alert us to the high prevalences of pain, underassessment and undertreatment in the elderly. Worldwide, numbers of elderly persons will increase substantially over the next decades, which only emphasizes the relevance of these issues.

The aims of this thesis were threefold:

1. To evaluate pain (management) in Dutch nursing homes;
2. To develop a reliable, valid and easy to use pain observation scale for those residents who are not able to report their pain themselves;
3. To implement the new scale in daily nursing practice.

In this chapter the main findings of our studies are discussed, and suggestions on future research directions are given.

MAIN FINDINGS AND CONCLUSIONS

1. Pain (management) in Dutch nursing homes

The starting point of this thesis was the fact that we found high prevalences and intensities of pain, mostly chronic, in four nursing homes in the Netherlands. A next study demonstrated that reports of proxies (e.g. caregivers and relatives) about the residents' pain were not always congruent, and tended to underestimate pain, especially in non-verbal and moderately to severely impaired residents. The shown behavior suggested even more pain in non-verbal residents and moderately to severely cognitively impaired than in mildly impaired and cognitively intact residents. Comparing pain treatment between groups of residents classified by cognitive/communication level resulted in a significantly larger proportion of non-verbal residents receiving no pain medication at all compared to cognitively intact to severely impaired residents.

This combination of too much pain – underestimated by caregivers – and the undertreatment, especially in cognitively impaired individuals, motivated our research project.

Non-pharmacological treatment

Some studies suggest that non-pharmacological interventions may be helpful to reduce pain.[1-3] Among the interventions proposed are music, relaxation therapy, and massage with or without aromatherapy. Although often not evidence-based, these interventions may still have beneficial effects from the inherent attention given to a person. In chapter 7 we demonstrated that non-pharmacological approaches were more frequent in non-verbal residents than in cognitively intact to

severely impaired residents. Although it remains a challenge, non-pharmacological treatment should be anchored more firmly in daily practice to demonstrate relevant effect. Perhaps it would be possible to have qualified volunteers perform these interventions, as caregivers are usually fully occupied with daily caring activities.

In the decision tree that comes with our newly developed pain scale, we suggest non-pharmacological interventions when pain scores are too high before considering pharmacological treatment.

Pharmacological treatment
In the main study, for each resident both routine and as needed analgesics were classified according to the World Health Organization (WHO) analgesic ladder, originally developed for cancer patients.[4] Step 1 consists of acetaminophen and NSAIDs, step 2 of weak opioids (e.g. tramadol) and step 3 of strong opioids (e.g. morphine). For nociceptive pain, medication from step 1 should be administered first; if the pain does not diminish, step 2-medication should be added. If this combination proves not effective enough, medication from step 1 should be administered together with medication from step 3. Neuropathic pain requires a somewhat different approach, i.e. administering co-analgesics (adjuvants).

Older adults often suffer from combinations of clinical conditions and symptoms, and therefore may experience either nociceptive pain or neuropathic pain alone, or a combination of both, which makes pharmacological treatment rather complex.[5, 6] Because older adults are at higher risk of adverse drug effects, due to e.g. reduced liver and kidney functioning, the rule of thumb for prescription of pain medication in older adults is 'start low, go slow'.[5, 7]

Barriers in pain treatment from the resident's point of view are fear for addiction, not being inclined to take (pain) medication, or believing that pain is inevitably part of aging.[8] From caregivers' and physicians' view, barriers are lack of good education about pain and pain therapies, and lack of evidence-based pain treatment protocols.[9] Residents, their relatives and caregivers should discuss consequences and side effects of analgesic treatment and possible non-pharmacological interventions in relation to the impact of the pain on the residents' life.

A more general barrier in pain treatment is the so-called 'as needed' prescribed pain medication. In our experience this type of prescription rarely results in administration. Non-verbal residents can not ask for the prescribed 'as needed' medication themselves, and have to rely on the caregivers' inclination to administer these.

2. The development of a reliable, valid and easy to use pain observation scale
Reviewing the available pain observation scales revealed that a reliable and valid scale for use in a heterogeneous nursing home population was lacking. Moreover,

treatment protocols based on well-established cut-off scores for pain were not provided. Therefore, we constructed a new scale, the Rotterdam Elderly Pain Observation Scale (REPOS), to assess pain in nursing homes residents who can not communicate themselves or have difficulty communicating their pain. We started with 138 behaviors in the pilot phase; in the end, ten valid pain-indicative behaviors remained.

With an eye on clinical practice, we aimed at an easy-to-use tool that takes only little time. Its construction was based on the experiences gained with comparable observation scales for neonates, children under the age of 3 years, and severely cognitively impaired children.[10-13] We aimed to measure the chronic pain older adults often suffer from.[14] Residents with chronic pain may exhibit social and emotional signs or specific body postures to express their pain as opposed to acute pain, which is rather expressed by facial reactions and vocalization. We, therefore, included residents with proven chronic pain conditions, and observed their behavior in situations that are especially painful, like washing or dressing. To make REPOS valid for a heterogeneous group of residents, we included all residents who were not able to report pain, such as residents with dementia, aphasia, and residents with acquired brain injury.

We acknowledge that special conditions may influence the REPOS score, so that a high score could indicate an emotion other than pain. To compensate for this possibility, nurses need to rate pain intensity on the Numeric Rating Scale (NRS) after having completed REPOS. REPOS scores of 3 and higher in combination with NRS 4 and higher indicates pain, and signal the desirability of further action.

The decision tree to this end provides several options, either non-pharmacological, e.g. relaxation therapy or distraction, or pharmacological. Finally, the tree always asks for a new observation after any intervention. The decision tree provided here must be seen as a blue-print, to be adapted to any specific population or setting.

In the Netherlands, Zwakhalen et al. translated and evaluated the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC), a pain observation scale for nursing home residents with dementia;[15] this resulted in the PACSLAC-D.[16] While REPOS consists of 10 items, the PACSLAC-D counts as many as 24. Specific behaviors, such as touching/holding sore area, guarding sore area, and pulling away, are separate items in PACSLAC-D, whereas REPOS combines these in one item, namely: moving body part. Two other items (aggression and uncooperative) of the PACSLAC-D were included in REPOS after the pilot phase, but were considered less relevant during the definitive construction. Moreover, the PACSLAC-D tends to focus more on social-emotional items, such as crankiness and not allowing people near. Overall, both scales are valid and easy to use in daily practice. Nursing homes should decide for themselves which scale is best suited for their daily practice.

3. The implementation in daily nursing practice

To enhance the use of REPOS, we developed an instruction chart that further explains the items, and also included a step-by-step decision tree for treatment interventions. Although REPOS appeared to be feasible, our first experience was that caregivers were not applying REPOS on a regular basis. Not surprisingly, lack of time was mentioned as main reason. Still, understaffing and busy days with time for caring activities only seem to be normal in nursing homes. In addition, staff nurses, physicians, and colleagues do not see pain observation as part of daily health care. Medical and nursing staff as role models should try to change this attitude.

Although we introduced a way to more objectively measure pain, we acknowledge that it may be influenced by individual differences in residents' pain experiences. In general, we should like to advocate a gain of knowledge on pain (treatment), and better communication between patients, their relatives, physicians, caregivers, paramedics, and psychologists as means to improve the detection, and consequently the treatment, of pain. Learning goals should include pharmacology, e.g. adverse effects of analgesics, as well as non-pharmacological interventions such as applying heat or cold, massage and distraction.

Barriers to successful implementation of a new assessment tool can emerge at different levels.[17] Here, we present some recommendations for implementing REPOS in daily practice:

- Management of the institution should be well informed from the start, and support the implementation.
- Medical staff should be interested in pain assessment, asking to be informed about high pain scores and acting upon it on the guidance of treatment protocols.
- Caregivers should be given the opportunity to use and document REPOS regularly, and train other colleagues, preferably using a train-the-trainer concept.
- Digitalising nursing and medical records will improve the feasibility and utility of REPOS. It has now been integrated into the computer program 'PlanCare' in several nursing homes in Rotterdam. Caregivers can easily enter scores in the computer, and view residents' scores over time.

Considering the positive experiences of the nurses who already use REPOS, including appreciation for ease of use, we believe the new method can certainly be successful. Moreover, the instructional cd-rom provided will help caregivers to learn how to apply REPOS.

To monitor quality of care in nursing home settings in the Netherlands, the Netherlands Health Care Inspectorate in 2007 has issued recommendations on

specific indicators for nursing homes.[18] National 'measurement weeks' are organized to score these indicators. A recent report suggested to include pain as a quality indicator.[19] Establishing information on the quality indicators has several aims: internal control information for management, professionals and client boards, external responsibility information for the Health Care Inspectorate, and information on choices for the consumer.[18] In anticipation, we assessed pain in all residents of a nursing home in Rotterdam in March 2008, either by self-report or REPOS. This yielded up-to-date data on pain prevalence in both communicating and non-communicating residents. We strongly believe that pain should be established as a quality indicator in Dutch nursing homes. In hospitals, this strategy has been proven a powerful tool to improve the quality of care.

Different types of dementia in clinical practice
Scherder et al. suggested that pain-related brain areas may function differently among various dementia groups, indicating possible differences in pain experiences.[20,21] Considering neuropathology and experimental and clinical data, they demonstrated diminished motivational-affective components of pain in patients with Alzheimer, and rather heightened ones in patients with vascular dementia, both compared to healthy controls.[22-24] Cole et al. found higher thresholds for pain sensitivity in patients with Alzheimer compared to controls, but no difference in ratings given for unpleasantness of painful stimuli. Based on functional brain imaging data (fMRI) they suggest that motivational-affective aspects of pain experience are not impaired in patients with Alzheimer. In addition, fMRI data support evidence of a more altered cognitive response to pain experience in Alzheimer's compared to controls.[25]

In our study, 23 residents with vascular dementia scored higher than 24 Alzheimer's patients, but not significantly. We feel, therefore, that it is not necessary to establish specific cut-off points for various types of dementia. For that matter, specific type of dementia is often not investigated in nursing home residents. For instance, of the 84 residents with dementia in our study, 24 residents (29%) were not diagnosed with MRI or CT-scan, and the neuropathological basis of dementia was therefore unknown.

FUTURE DIRECTIONS

Though REPOS has promising validity, further studies are indispensable. For instance, sensitivity to change needs to be studied by completing REPOS before and after administration of analgesics or before and after surgery.

Patients with dementia often show behavioral deviations, such as quick irritation, emotional outbursts, and mood changes. It is difficult to examine, however, whether a person would display these behaviors in the absence of pain or whether

those might have been aggravated by pain. The best feasible solution would be to carefully observe the effects of analgesics on such behavioral deviations. PACSLAC-D contains many more social-emotional behaviors than does REPOS, a comparison study with sufficient numbers of patients could be interesting to determine the relevance of these behaviors in measuring pain.

To extend its potential, REPOS should be applied and studied in other populations than nursing home residents, three of which deserve mention.

Adults with profound cognitive impairment
The Checklist Pain Behavior for children with profound cognitive impairments was found not useful in (older) adults during our pilot phase. As REPOS was based on this scale, a next study group will be the growing population of adults with profound cognitive impairments. These individuals are likely to suffer from chronic pain because of their medical conditions and/or physical disorders, e.g. contractures, scoliosis, epilepsy, gastro-esophageal refluxes, often present since their childhood.[10] Another group of interest are persons with Down's syndrome; as their life expectancy is increasing,[26,27] they are getting higher risk of developing Alzheimer's disease.

(Older) adults in hospitals
Because pain is common in hospitalized patients, research is needed to validate REPOS in this population. A worthwhile focus of interest is postoperative pain in patients with communication problems and geriatric patients. In 2005 we performed a pilot study in 52 patients admitted to a geriatric ward of an academic hospital. Assessment of self-reported pain proved impossible in 15 of them, with cognitive impairment as main reason. Twenty of the other 37 reported a pain score of 4 or higher. Considering these alarming findings, REPOS could be useful at a geriatric hospital ward.

Terminally ill patients
Good palliative care in patients in the end-stage of life is difficult. Pain can be a major aspect: it occurs in about 70% of patients with advanced cancer. According to a large European survey in 2007 half of European cancer patients have moderate to severe pain, and one in five patients does not receive treatment.[28] A Dutch study reported inadequate pain treatment in 42%.[29] At the end-stage of life, patients are often sedated and communication is hardly possible. 'Doctor, is my mother/father in pain?' is a much asked question. This question can not be easily answered, because little is known about pain perception in terminally ill patients.

In an eight-bed palliative care unit in one of the participating nursing homes described in this thesis, about a hundred residents yearly die, of whom most have been diagnosed with cancer. In 2005 we trained two nurses on this unit to use REPOS. Forty REPOS and NRS scores were completed in 12 patients, all receiving

strong opioids in combination with one or more sedatives. The median REPOS score for caring activities was 3 and for rest situations it was 0. One third of all observations suggested pain. These preliminary findings suggest that REPOS may be applicable in terminally ill cancer patients.

Sedation complicates the assessment of pain. How do we know a sedated patient is not feeling any pain? A pilot study in which patients will be observed while they are connected to a Bispectral Index (BIS) monitor attempts to answer this question. The BIS monitor is considered a reliable and valid instrument to assess sedation depth, at least in perioperative conditions and in critically ill sedated intensive care patients over six months of age. Preliminary results suggest that the BIS monitor is clinical applicable and can be a helpful tool in assessing level of awareness in dying patients as well. BIS values in twelve terminally ill patients collected from the moment they became unconscious until prior to death showed a decline.[30] A case study in a terminally ill patient showed decreasing BIS values in combination with stable morphine doses. Nurses therefore considered the BIS a helpful tool to monitor the dying process.[31]

Pharmacological studies

Pharmacodynamic and pharmacokinetic studies in elderly are scarce. Many questions remain, for instance on the extent to which decline in renal and liver functioning affects drug metabolism. Another concern is polypharmacy, as this is common in older adults.[32] Overall, limited information is available about the interaction-effects and long term effects of taking many different medications. Yet, Milton et al. (2008) noted increasing research efforts on prescription practices in the elderly. They presented ten guidelines for good prescribing in elderly patients, e.g. stop any current drugs that are not indicated, prescribe new drugs that have a clear indication, consider non-pharmacological treatments, and limit the number of people prescribing for each patient.[33]

A closer look at pain in nursing home residents

The growing attention to pain in older adults is paralleled by an increase in pain studies.[34-38] The American Pain Society recommends pain should be considered as the fifth vital sign, so as to heighten awareness of pain (treatment).

As the 'gold standard' of self-report is not always possible in moderately to severely cognitively impaired and non-verbal residents, we should take refuge to the 'silver standard' of pain, namely assessing pain on the basis of specific pain behavior. Cognitively intact and mildly impaired older adults, however, are known to have short-term memory problems, and self-report can not automatically be seen as a valid way to assess pain in these persons. Moreover, older adults are known to be reluctant to complain, have a tendency to resist (too much) medication, or simply are convinced that pain is normal in later life. As a means to counteract older adults' underreport of pain, we believe that regular pain assessments according to a

standardized observation scale, such as REPOS, is also helpful to assess pain in older adults who are able to report pain themselves.

Our initial goal was to assess pain in older adults living in a nursing home. Soon after including the first residents, however, we realized that nursing home residents need not be 'old'. Therefore, we adjusted our goal into a more heterogeneous perspective, focusing on all nursing home residents who could not communicate their pain by completing the Numeric Rating Scale. The name of our scale therefore does no justice to the full target group, as this includes adults younger than 65 years as well. Nevertheless, we trust that this thesis will make clear that REPOS can be used to determine pain more objectively in a wide range of nursing home residents.

Finally, in the past few years we experienced that taking a closer look at nursing home residents subtly reveals the things that otherwise may go unnoticed.

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10

Summary & Samenvatting

SUMMARY

Pain is a highly prevalent condition among older adults (40 to 85%), and aging of our population will continue until 2050. Therefore, pain is one of the aspects within the health care system that needs special attention. Assessing and treating pain adequately is a great challenge, especially in cognitively impaired and non-verbal persons. A standardized, reliable and valid pain observation scale together with a decision tree for treatment is needed to improve the documented underassessment and –treatment of pain. In 2002, no such scale was available, and therefore we started a study in which we aimed to develop and implement a reliable, valid and clinical useful observation scale to measure pain in nursing home residents who were not able to report pain themselves.

The aim of **Chapter 2** was to explore the occurrence of pain in daily life in Dutch nursing homes. Residents of four homes were asked several questions about their pain and pain treatment. Residents with cognitive limitations as judged by the staff nurse were excluded (17%). Intensity of pain was assessed on the reliable and valid Numeric Rating Scale (NRS), ranging from 0 (no pain) to 10 (most imaginable pain). Of the 233 included participants we found 153 residents (66%) experiencing pain, mostly chronic, with a median pain intensity of 5. Furthermore, 41% of the hundred residents who were able to report their tolerable pain intensity reported their pain as intolerable. More than half of those residents in pain, reported interference with sleep, physical care and other activities; about 60% were feeling tense and/or depressed. Twenty-five per cent of the residents in pain did not receive any pain medication. Proportions of residents who reported that nurses and physicians pay enough attention to their pain complaints varied between 40% to 80% for the different homes. In conclusion, considering the high prevalence, intensity and amount of intolerable pain, and interference with other activities, awareness and knowledge of pain management should be improved.

Chapter 3 describes the results of a multicenter cohort study in which pain reports of nursing home residents were compared to the pain scores as judged by their proxies, i.e. caregivers and relatives. The aim of the study was to evaluate the utility of proxies for the assessment of pain in nursing home residents, and different aspects influencing proxy reports. One hundred and seventy-one nurses and 122 relatives were interviewed about several pain aspects of cognitively intact to severely impaired and non-verbal residents.
All three parties rated median pain intensity during the preceding week as 6.0. Results showed low to moderate intraclass correlation coefficients between residents and caregivers, residents and relatives, and caregivers and relatives. Pain intensity at rest was judged significantly higher by residents than proxies. Caregivers scored significantly higher pain intensities if residents were prescribed analgesics, and significantly lower pain intensities if residents were more satisfied with the prescribed analgesics. Relatives reported significantly higher pain

intensities in intact residents compared to impaired residents. We concluded that reports of pain presence and pain intensity by proxies are not always reliable and in agreement, especially in severely cognitively impaired and non-verbal persons. Our findings suggest an urgent need for a more objective way to measure pain.

Chapter 4 is a review on 17 existing pain observation scales used or developed for older adults (till February 2008). As the available scales employ different methods of evaluating reliability and validity, and pursue different aims (e.g. type pain), they cannot easily be compared. A few of the pain observation scales, however, were found to be promising by the preliminary validation results. Further examination of psychometric properties and their usefulness in different scales is warranted. Also, more specific attention should be aimed at developing a treatment protocol based on well-established cut-off scores for pain. Pain observation scales should at least be tailored to the unique characteristics and needs of the (older) adult with communication difficulties. Until a reliable and valid observation scale has been developed, we recommend that patients with one or more probable painful diagnoses who are not able to communicate, should be treated as if they are in pain, with caregivers using the most promising pain scale to observe the presence of specific pain behaviors.

We performed an empirical-explorative pilot study to construct a new pain observation scale for older adults **(Chapter 5)**. In the first part of this study, we aimed to make an inventory of overt behavior that represents pain expression in nursing home residents. In the second part, eight purpose-trained field experts observed videotaped behavior of 14 nursing home residents, aiming to identify the most reliable and valid pain behaviors and also those behaviors which are not useful. The observers independently scored as many as 138 items of the original Checklist Pain Behavior (CPG) as absent, sometimes present, often present or always present. To detect the most frequent and most differentiating pain items, a stepwise item reduction procedure was followed, which eventually resulted in fourteen pain-indicative behaviors:

1. tense face
2. grimace
3. eyes (almost) squeezed
4. raising upper lip
5. frightened/fearful look
6. panicky, panics attack
7. not cooperating
8. seeking comfort
9. aggression/anger
10. moving body part
11. sounds of restlessness
12. moaning/groaning
13. crying softly
14. holding breath/faltering respiration

These items showed promising results in terms of reliability and validity. In a next phase, the interrelationships and dimensional structure of these 14 pain behaviors were determined in order to develop the final instrument.

Chapter 6 describes the co-occurrences and interrelationships between the 14 items found in Chapter 5. Furthermore, the psychometric properties of the new scale are determined in a larger sample of nursing home residents. The main objective of this chapter was to develop an easy-to-use, reliable and valid observation instrument to measure pain in nursing home residents for whom self-report is impossible. In a multicenter case-control design, 124 cognitively impaired and non-verbal and 50 mildly cognitively impaired and cognitively intact nursing home residents were observed during a painful situation and at rest. The item 'crying softly' was removed because it was prevalent in less than 5% of the cases, and three other items were redundant after a regression analysis. After having identified the interrelationships of the items in terms of a clinical-empirical structure, the Rotterdam Elderly Pain Observation Scale (REPOS) eventually comprised ten items, which need to be scored absent (= 0) or present (= 1). Despite the moderate internal consistency, REPOS appears to be a valid assessment to measure pain in a wide range of nursing home residents with varying cognitive levels and even non-verbal residents. The cut-off score for pain was three and higher, based on good sensitivity and specificity values. As REPOS is concise, and a step-by-step decision tree for treatment interventions is provided, we expect caregivers will find it easy to master and use it in daily practice, which is the focus of the subsequent implementation phase.

In **Chapter 7** we compared pain behavior and pain treatment between three groups of nursing home residents based on their cognitive/communication level (MMSE). Of 172 residents, 67 were non-verbal, 55 were moderately to severely cognitively impaired, and 50 were mildly impaired or cognitively intact. Pain during a painful situation was assessed with REPOS, and pain in the previous week with Doloplus-2 and the Numeric Rating Scale (NRS). Pain according to REPOS was significantly different for the three groups (P = 0.04), of which group 3 scored lowest. Mean Doloplus-2 score and NRS did not differ significantly among the groups. The non-verbal residents received significantly less analgesics than the cognitively impaired and intact residents, but received more non-pharmacological interventions. Most nurses (75%) were satisfied with the prescribed analgesics. Residents who were treated inadequately according to NRS, ranged from 59% to 69%. Based on REPOS scores, PMI scores were found inadequate in 71%, 75%, and 43%, respectively.
Awareness and knowledge about pain assessment and treatment need to be improved in daily practice.

In **Chapter 8** the implementation of REPOS in practice was evaluated. Fifteen nurses followed a skills training. During a theoretical part they learned how to observe the specific REPOS items by viewing several video tapes of residents. In the clinical part of the training, they observed residents at the bedside together with the teacher for two minutes and afterwards complete REPOS independently. All nurses reached a sufficient Cohen's kappa (median 0.65; IQR 0.63 to 0.74) within 4 to 10 weeks (median 8). During this period they had a median of 12 bedside

observations (IQR 11 to 13). Twelve of the participants needed one or two more training sessions by observing videos. After nurses were considered competent to complete REPOS independently, they were asked to make observations in residents not able to communicate who were assumed to be in pain. In a period of six months 52 REPOS observations were completed by seven caregivers at five different wards. A combination of a high REPOS score (≥ 3) and a high NRS score (≥ 4) was found in 42% of observations, and in 77% of these an action was reported. In conclusion, the one-to-one clinical training was found to be a good option to learn using REPOS in a reasonably short time. REPOS appears to be feasible to assess the often complex chronic pain in nursing home residents.

Finally, in **Chapter 9**, the main findings of this thesis are discussed. Furthermore, the preliminary results of several pilot studies are described, and recommendations for future studies are provided.

SAMENVATTING

Pijn komt veel voor onder ouderen: de prevalentie wordt op 40 tot 85 procent geschat. De vergrijzing van onze bevolking zal naar verwachting doorgaan tot 2050. Daarom is pijn één van de aspecten binnen de gezondheidszorg die speciale aandacht vereist. Het adequaat meten en behandelen van pijn is een grote uitdaging, met name bij cognitief beperkte en niet-communicatieve personen. Er is behoefte aan een gestandaardiseerde, betrouwbare en valide pijnobservatieschaal in combinatie met een beslisboom voor non-farmacologische en farmacologische behandeling. Het gebruik van zo'n schaal zou de onderrapportage en –behandeling van pijn kunnen verbeteren. In 2002 was zo'n instrument nog niet beschikbaar. Het Pijnkenniscentrum Rotterdam is in de lijn van onderzoek bij andere groepen wilsonbekwamen, zoals pasgeborenen en verstandelijk gehandicapte kinderen, gestart met het ontwikkelen en implementeren van een betrouwbare, valide en klinisch bruikbare pijnobservatieschaal bedoeld voor verpleeghuisbewoners die niet in staat zijn zelf hun pijn te uiten.

Het doel van de studie in **Hoofdstuk 2** was het in kaart brengen van pijn in het dagelijkse leven van bewoners van vier Nederlandse verpleeghuizen. De bewoners werden benaderd om een aantal vragen over hun pijn en pijnbehandeling te beantwoorden. Uitgesloten werden echter bewoners met cognitieve beperkingen (17%). De bewoners werd gevraagd de intensiteit van eventuele pijn aan te geven op een numerieke schaal van 0 (geen pijn) tot 10 (ergst denkbare pijn). Van de 233 participanten had 68% pijn, veelal chronisch, met een mediane intensiteit van 5. Daarnaast rapporteerde 41% hun pijn als ondraaglijk. Meer dan de helft van de bewoners rapporteerde slaapproblemen, moeite met fysieke verzorging en andere activiteiten, en ongeveer 60% voelde zich gespannen en/of somber als gevolg van hun pijn. Een kwart van de bewoners met pijn kreeg geen enkele vorm van pijnmedicatie. Tussen de 40 en 80% van de bewoners (variërend per verpleeghuis) gaf aan dat verpleegkundigen en artsen voldoende aandacht hadden voor hun pijnklachten. Gezien de hoge pijn prevalentie, de hoge intensiteit en de hoge mate van voorkomen van ondraaglijke pijn, alsmede de negatieve invloed daarvan op andere activiteiten, concluderen we dat pijnmeting en –behandeling alle aandacht behoeven.

Hoofdstuk 3 beschrijft de resultaten van een onderzoek, waarin pijnscores door de verpleeghuisbewoners zelf worden vergeleken met de pijnscores gerapporteerd door hun proxies, dat wil zeggen verzorgenden en familieleden. Het doel was om na te gaan of proxy-rapportage wellicht bruikbaar is voor het bepalen van pijn van de bewoners, en welke aspecten hierop van invloed waren. Interviews werden afgenomen met 171 verzorgenden en 122 familieleden van cognitief intact tot cognitief beperkte en non-communicatieve bewoners. Zowel de bewoners zelf als beide proxy-groepen gaven een mediane intensiteit van 6 aan voor pijn in de voorgaande week. De pijnintensiteit in rust werd significant hoger beoordeeld door

de bewoners dan door de proxies. De intraclass correlatiecoëfficiënten tussen bewoners en verzorgenden, bewoners en familieleden, en verzorgenden en familieleden, waren laag tot matig. Verzorgenden gaven significant hogere pijnscores voor die bewoners die pijnmedicatie kregen, en significant lagere als zij meer tevreden waren over de voorgeschreven pijnmedicatie. Familieleden rapporteerden een significant hogere pijnintensiteit bij cognitief intacte bewoners dan bij cognitief beperkte bewoners. We concludeerden dat proxy-rapportage niet altijd betrouwbaar was, met name voor ernstig cognitief beperkte en non-communicatieve personen. Er blijft derhalve een grote behoefte aan een meer objectieve manier om pijn te meten.

Hoofdstuk 4 is een review van 17 bestaande pijnobservatieschalen voor ouderen (tot februari 2008). Omdat deze voor verschillende types pijn en situaties zijn ontwikkeld, en de betrouwbaarheid en validiteit zijn vastgesteld aan de hand van verschillende methoden, is vergelijking niet gemakkelijk. Echter, de voorlopige psychometrische kwaliteiten van sommige zijn veelbelovend. Meer onderzoek is nodig naar psychometrische eigenschappen en bruikbaarheid van verschillende schalen alvorens definitief een keuze te kunnen maken voor de optimale pijnschaal. Daarnaast verdient de ontwikkeling van een behandelprotocol gebaseerd op een reëel afkappunt voor pijn speciale aandacht. Pijnobservatieschalen zouden in ieder geval moeten zijn geënt op de eigenschappen en behoeftes van ouderen met communicatieproblemen. Zolang een betrouwbare en valide observatieschaal nog niet beschikbaar is, adviseren wij bewoners die niet kunnen communiceren maar hoogstwaarschijnlijk toch pijn hebben te behandelen alsof ze pijn hebben. Veelbelovende pijnschalen kunnen dan worden gebruikt om de aanwezigheid van specifieke pijngedragingen te observeren.

We hebben een empirisch-exploratieve pilot-studie uitgevoerd om tot een nieuwe pijnobservatieschaal voor ouderen met uitingsbeperkingen te komen (**Hoofdstuk 5**). Ons eerste doel was een inventarisatie te maken van expliciete gedragingen bij verpleeghuisbewoners die duiden op pijnexpressie. Vervolgens hebben acht pijnexperts het gedrag van 14 verpleeghuisbewoners op video geobserveerd met als doel de meest betrouwbare en valide pijngedragingen te identificeren, maar ook de gedragingen die niet geschikt zijn uit te sluiten. Observatie gebeurde aan de hand van de Checklist Pijn Gedrag (CPG) met 138 items, die ontwikkeld is voor ernstig verstandelijk gehandicapte kinderen. Een stapsgewijze procedure resulteerde uiteindelijk in veertien gedragingen die pijn aantonen:

1. gespannen gezicht
2. grimas
3. ogen (bijna) dichtknijpen
4. optrekken bovenlip
5. angstig kijken
6. paniekerig, paniekreactie
7. niet meewerken
8. troost zoeken
9. agressie/boosheid
10. bewegen lichaamsdeel
11. onrustgeluiden
12. kreunen/jammeren
13. zacht huilen
14. inhouden adem/stokken ademhaling

Wat betreft de betrouwbaarheids- en validiteitsbepaling laat deze set items veelbelovende resultaten zien. Een volgende stap is inzicht verkrijgen in de interrelaties en dimensionale structuur van deze 14 gedragingen, waarna uiteindelijk het definitieve instrument kan worden ontwikkeld.

Hoofdstuk 6 beschrijft in hoeverre de 14 gedragingen die werden geselecteerd in de vorige fase, samen voorkomen, en welke interrelaties er zijn. Daarnaast werden de psychometrische eigenschappen onderzocht in een grotere populatie verpleeghuisbewoners. Het belangrijkste doel van dit alles was te komen tot een gemakkelijk te gebruiken, betrouwbaar en valide observatieschaal om pijn vast te stellen bij verpleeghuisbewoners voor wie zelfrapportage onmogelijk is. In een multicenter *case-control* design zijn 124 cognitief beperkte en non-communicatieve bewoners en 50 licht cognitief beperkte en cognitief intacte bewoners geobserveerd tijdens een pijnlijke situatie en in rust. Naar aanleiding van de resultaten werd het item 'zacht huilen' geschrapt, omdat het bij minder dan 5% van de bewoners was gezien. Drie andere items bleken overbodig na een regressie-analyse. De uiteindelijke schaal, die we de Rotterdam Elderly Pain Observation Scale (REPOS) hebben genoemd, bestaat derhalve uit tien items. Deze dienen te worden gescoord als afwezig (= 0) of aanwezig (= 1). Ondanks de matige interne consistentie lijkt de REPOS een valide instrument om pijn te meten bij een brede groep verpleeghuisbewoners. De score van 3 als afkappunt voor pijn is gebaseerd op een goede sensitiviteit en specificiteit. De REPOS is kort en bondig, en er is een beslisboom aan toegevoegd die eventueel verder te nemen acties aangeeft. Dit maakt naar verwachting de REPOS gebruiksvriendelijk in de dagelijkse praktijk. Of dit werkelijk zo is zal in de implementatiefase worden geëvalueerd.

In **Hoofdstuk 7** hebben we pijngedrag en pijnbehandeling vergeleken tussen drie groepen verpleeghuisbewoners geclassificeerd naar hun cognitieve/communicatieve niveau gemeten met de *Mini Mental State Examination* (MMSE). Van de 172 bewoners waren 67 niet-communicatief (groep 1), 55 matig tot ernstig cognitief beperkt (groep 2), en 50 waren mild beperkt of cognitief intact (groep 3). Pijn tijdens een pijnlijke situatie was gemeten met REPOS en pijn in de afgelopen week met de Doloplus-2 en de Numerieke Rating Schaal (NRS). De REPOS scores waren significant verschillend voor de drie groepen (P = 0.04), waarbij groep 3 het laagst scoorde. De gemiddelde Doloplus-2 totaalscores en de NRS verschilden niet van elkaar. De niet-communicatieve bewoners kregen significant minder pijnmedicatie voorgeschreven dan de cognitief beperkte en intacte bewoners, maar kregen meer niet-farmacologische interventies. De meeste verzorgenden (75%) waren tevreden over de voorgeschreven analgetica. De Pijn Management Index (PMI) werd berekend op basis van de zelf-rapportages, de rapportages van de verzorgenden en de REPOS. Hoge percentages bewoners met inadequate pijnbestrijding werden gevonden (59% tot 69%). Gebaseerd op de REPOS, werden meer bewoners in de niet-communicatieve groep en de matig tot ernstig cognitief beperkte bewoners inadequaat behandeld vergeleken met groep 3. Er is nog meer aandacht nodig in de

dagelijkse praktijk voor pijnmeting aan de hand van een observatieschaal, alsmede voor de maatregelen om de pijn weg te nemen.

In **Hoofdstuk 8** is de implementatie van de REPOS in de praktijk geëvalueerd. Voor dit doel werden vijftien verzorgenden geschoold in het gebruik van de REPOS. Tijdens een theoretisch gedeelte leerden zij de specifieke REPOS items te observeren door het bekijken van verschillende videofragmenten van bewoners. Daarna hebben zij minimaal tien bewoners aan het bed geobserveerd samen met de trainer, en vervolgens onafhankelijk gescoord. Alle verzorgenden bereikten voldoende interbeoordelaarsbetrouwbaarheid met de trainer (mediane Cohen's kappa 0.65; IQR 0.63 tot 0.74) binnen 4 tot 10 weken (mediaan 8). Dit was na gemiddeld 12 observaties (IQR 11 tot 13). Twaalf van de verzorgenden deden 1 of 2 extra video-observaties. Vervolgens werden REPOS observaties verricht bij bewoners die niet in staat waren om hun pijn te communiceren en waarbij pijn werd verondersteld. In een periode van zes maanden werden 52 observaties verricht door zeven verzorgenden op vijf verschillende afdelingen. Uit 42% van deze observaties kwam een combinatie van een hoge REPOS score (≥ 3) en een hoge NRS score (≥ 4) naar voren; in 77% daarvan werd actie ondernomen. We concluderen dat de één-op-één klinische training een goede manier is om binnen een redelijk korte termijn de REPOS te kunnen gebruiken.

Tot slot, in **Hoofdstuk 9** worden de belangrijkste bevindingen beschreven. Daarnaast worden de resultaten van een aantal pilot-studies besproken en aanbevelingen voor toekomstige studies gedaan.

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Curriculum Vitae

CURRICULUM VITAE

Rhodee van Herk was born on the 10th of June 1977 in Breda, the Netherlands. In 2000, she obtained a master's degree at the Faculty of Social and Behavioural Sciences in the University of Amsterdam. After her study, she was a research-assistant in the department of Child and Adolescent Psychiatry in Erasmus MC-Sophia for one year. Here she worked on a project about quality of life in children with psychiatric disorders.
From February 2002 through February 2008 she has developed her own research project at the Pain Expertise Center Rotterdam, which has resulted in this thesis. The study was performed in close collaboration with the Pain Research Group of the department of Pediatric Surgery, Erasmus MC-Sophia.
She is married to Eric Dorenbos and lives in Dinteloord, the Netherlands.

Overzicht voordrachten & ontwikkeling

Presentaties/workshops		**Belasting (uren)**
2005	Integraal Kankercentrum West (IKW)	4
2006	Congress Anesthesia and Perioperative Care in the Older Patient (APCOP), Rotterdam	4
	Integraal Kankercentrum Amsterdam (IKA), Lelystad	4
	AGORA; 'Palliatieve zorg voor mensen met een verstandelijke beperking: een gezamelijke uitdaging', Utrecht	4
	Intergraal Kankercentrum Amsterdam (IKA), 'Dementie en palliatieve zorg', Schagen	4
	Intergraal Kankercentrum Amsterdam (IKA), 'Dementie en palliatieve zorg', Alkmaar	4
	Nationaal Congres Palliatieve Zorg 'terugblikken en vooruitzien', Lunteren	16
	Pain conference: 'Pain in dementia: new challenges', Groningen	10
2007	Erasmus MC, AVG opleiding; 'De AVG, daar zit muziek in', Rotterdam	4
	Ontwikkelingen in de palliatieve zorg; seminar voor gevorderden, georganiseerd door PAOG-IKO, Driebergen	4
	Pijnconferentie 'Stop onnodige pijn bij kwetsbare ouderen'; georganiseerd door ActiZ, NVVA, en Nationaal Pijnfonds, Utrecht (voordracht en workshop)	8
Scholing voorbereid/gegeven		
2003	Checklist Pijn Gedrag (CPG)	4
2007	Rotterdam Elderly Pain Observation Scale (REPOS)	8
Poster presentaties internationale congressen		
2003	Pain in Europe IV, Congress of the European Federation of IASP Chapters (EFIC), Prague The development of a pain observation scale for cognitively impaired patients. R van Herk, R de Wit, D Tibboel, FPM Baar. Book of abstracts: p 158.	8
2006	Pain in Europe V, Congress of the European Federation of IASP Chapters (EFIC), Istanbul	36
	Introducing the reliable and valid Rotterdam Elderly Pain Observation Scale (REPOS). R van Herk, M van Dijk, R de Wit, D Tibboel, HJ Duivenvoorden. Eur J Pain 2006, 10 (Suppl 1): p 132.	
	Perceptions of pain in a geriatric in-hospital population. R van Herk, R de Wit, T van der Cammen, D Tibboel, M van Dijk. Eur J Pain 2006, 10 (Suppl 1): p 233.	
Nederlandse publicaties		
2004	R van Herk, R de Wit, D Tibboel, FPM Baar. Is pijn meten mogelijk bij ouderen met een uitingsbeperking? Pijn Info 2004;2:53-69.	
2007	AA Boerlage, R van Herk, SJ Swart, FPM Baar. Observatie van pijn: pijnmeting bij mensen met een uitingsbeperking. Pallium 2007;9:10-13.	
Medewerking aan televisieprogramma		
2004	EO, Intensive Care. Pijn bepalen bij mensen met een uitingsbeperking	

Appendices

Rotterdam Elderly Pain Observation Scale (REPOS)

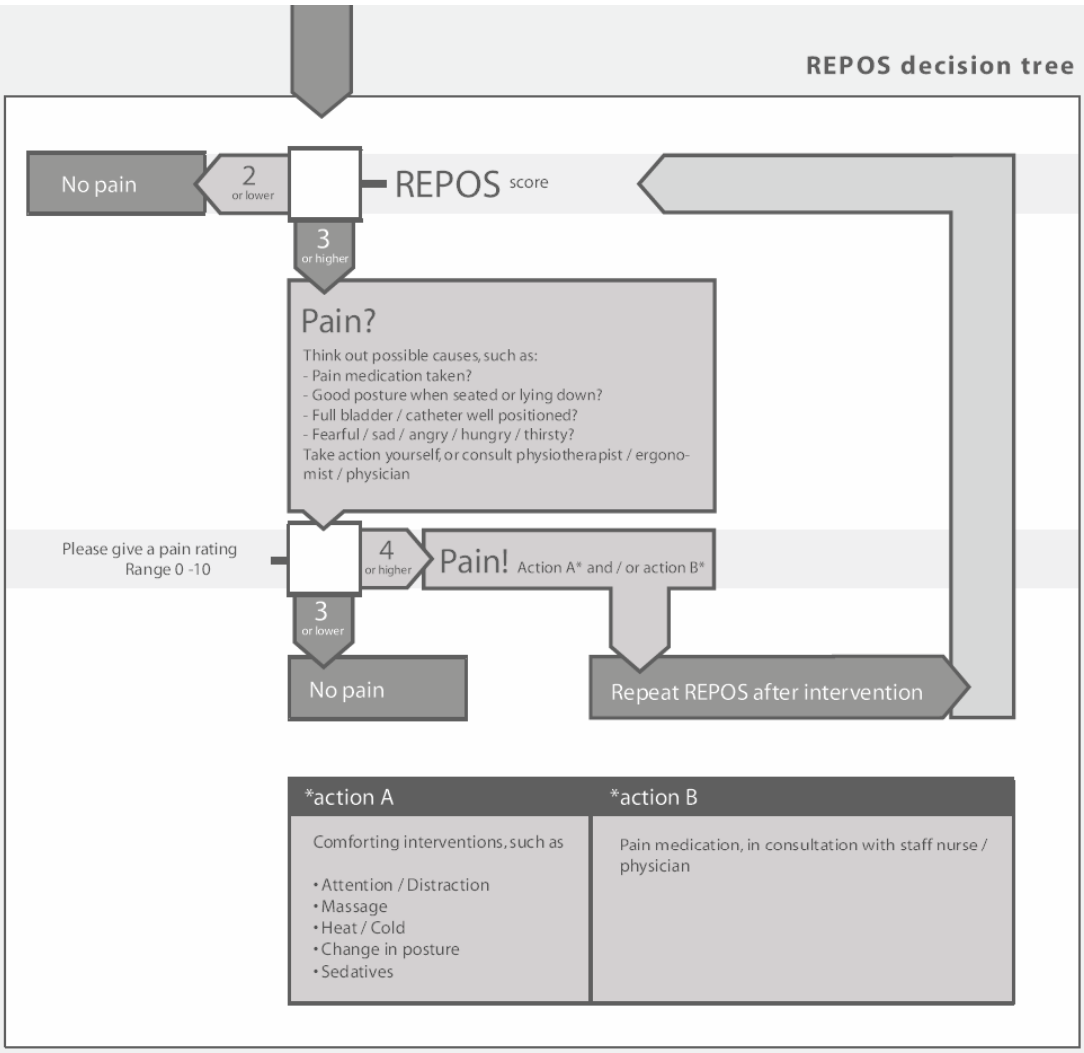
Please observe for 2 minutes, and tick the box if the specific behavior was present during the observation. Next, summate all ticked behaviors to obtain the REPOS total score.

NAME CLIENT	1st observation	2nd observation	3rd observation
NAME OBSERVER			
DATE/TIME			
SITUATION (ADL, transfer, walking, physical therapy, rest, wound care, e.g.)			
PAIN MEDICATION (type, dosing and time of last administration)			

Tense face	☐	☐	☐
Eyes (almost) squeezed	☐	☐	☐
Raising upper lip	☐	☐	☐
Grimace	☐	☐	☐
Frightened, fearful look	☐	☐	☐
Moving body parts	☐	☐	☐
Panicky, panics attack	☐	☐	☐
Moaning / groaning	☐	☐	☐
Sounds of restlessness / verbal expressions	☐	☐	☐
Breath holding / faltering respiration	☐	☐	☐
REPOS TOTAL SCORE	☐	☐	☐
	see REPOS decision tree	see REPOS decision tree	see REPOS decision tree

REPOS© versie 1.2, Van Herk, Boerlage, Van Dijk, Erasmus MC 2008

REPOS decision tree



Please enter the REPOS score and pain rating in the schedule below, as well as the action taken.
The pain rating ranges from 0 (no pain) to 10 (worst imaginable pain).

NAME CLIENT

	1st observation	2nd observation	3rd observation
NAME OBSERVER			
DATE/TIME			
REPOS score			
PAIN RATING			
ACTION			

Rotterdam Elderly Pain Observation Scale (REPOS)

Instruction chart

Definitions of the behaviors

Each item in the REPOS represents specific behavior or a certain reaction. The REPOS does not score intensity of behavior, but rather occurrence, yes or no. An item is only scored as present if the behavior in question was clearly visible. Scoring is not useful if the client is in relaxed sleep.

Tense face
One or more facial muscles are being tightened (are not relaxed).
This is NOT scored when client is talking.

Eyes (almost) squeezed
Eyes tightly shut or squeezed.
Do NOT score if client shows blinking eyes or eyes shut without squeezing.

Raising upper lip
The upper lip is being pulled up, shortening the distance between upper lip and nose; nasio-labal furrows deepened, nostrils raised and enlarged.

Grimace
Scored as present only when the following three facial expressions occur together:
1) Eyebrows drawn together and downward, with the skin fold between the eyebrows bulged out.
2) Eyes tightly shut or squeezed.
3) Nasio-labal furrows deeper than normal and drawn up sideways.

Frightened, fearful look
Large, widely opened eyes, and inner sides of eyebrows slightly raised and drawn together.

Moving body parts
Each movement indicative of resistance or protecting a (painful) body part. Included are movements such as changing one's position in a chair so as to relieve one's bottom, and grasping the head.
Do NOT score when the movement or action is functional, e.g. pushing one's hair out of one's face, or raising arms to take off clothes.

Panicky, panics attack
An extreme manifestation of anxiety showing in random nervous body movements or fierce resistance.
This may co-occur with:
- *Frightened expression characterized by large, widely opened eyes, and inner sides of eyebrows slightly raised and drawn together; and/or*
- *Intense screams or verbal expressions of pain, such as 'ouch' or "you're hurting me'.*

Moaning/groaning
Monotonous and whining sound.

Sounds of restlessness/verbal expressions
Sudden or persisting intense screams or verbal expressions of pain, such as 'ouch' or "you're hurting me'.

Breath holding/faltering respiration
Briefly interrupted breathing, gasping.