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Pain in Alzheimer's disease: nursing assistants' and patients' evaluations

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Pain in Alzheimer's disease: nursing assistants' and patients' evaluations

Aim. This paper reports on a study examining the level of agreement between the pain perceptions of nursing assistants, older people without dementia and patients with Alzheimer's dementia. It was hypothesized that nursing assistants would overestimate the pain experience of patients with Alzheimer's dementia.

Background. There is now increasing evidence that, in contrast to other subtypes of dementia, patients with Alzheimer's disease might experience a decrease in pain. It is unfortunate that these latest insights into the complex relationship between subtypes of dementia and pain are not always included in education programmes for nursing assistants.

Method. Twenty patients with Alzheimer's disease and 17 older people with arthritis and/or osteoporosis but no dementia and their personal nursing assistants participated in the study. Pain experience was assessed using the Coloured Analogue Scale for the assessment of Pain Intensity and Pain Affect, the Faces Pain Scale, and the Checklist of Non-verbal Pain Indicators. The data were collected in 2002–2003.

Results. Before and after walking, the absolute difference in pain evaluation between nursing assistants and older people without dementia was statistically significantly less than the difference in pain evaluation between nursing assistants and patients with Alzheimer's disease on the Coloured Analogue Scale for Pain Intensity ($P = 0.007$ and $P = 0.04$, respectively) and on the Coloured Analogue Scale for Pain Affect ($P = 0.009$ and $P = 0.01$, respectively).

Conclusion. Nursing assistants may overestimate the extent of suffering from pain of patients with Alzheimer's disease. They might be very well able to estimate this pain, provided they were educated about new insights into the influence of the various subtypes of dementia on pain.

Keywords: Alzheimer's disease, pain, pain assessment, nursing assistants

Background

Pain assessment in cognitively impaired older people is complex (Marzinski 1991, Ferrell 1995), and is often a reason for excluding them from pain studies (Wynne *et al.* 2000). A reflection of this complexity might be that older people with cognitive impairment use fewer analgesics than those who are

cognitively intact (Marzinski 1991). One possible explanation is that the neuropathology in, for example, Alzheimer's disease (AD) might alter the actual pain experience (Scherder *et al.* 2003a). Many areas of the brain that are affected in AD (e.g. the prefrontal cortex, anterior cingulate cortex, and hippocampus; Braak & Braak 1991), are also involved in processing the affective components of pain (Treede *et al.*

1999). Some of these areas, e.g. the hippocampus, are already affected at an early stage of AD (Braak & Braak 1991).

A lower use of analgesics in patients with dementia might also reflect an *undertreatment* of pain. First, a patient with dementia may underreport pain because he has forgotten that he was in pain. However, a recent study that reduced the impact of memory by assessing pain in patients with AD repeatedly, that is, daily at varying times and during different periods, showed that, irrespective of the assessment frequencies and periods, patients with AD were still reported to experience less intensity and effect of pain than older people without dementia (Scherder *et al.* 2001). Alternatively, one might wonder whether carers are capable of identifying pain in older persons. In a study by Middleton *et al.* (1997) no significant differences in pain ratings were observed between residents, Residents' Assistants (RAs) and Registered Nurses (RNs). It is worth noting that only the pain ratings of the cognitively intact older people were compared with the ratings of both the RAs and the RNs. Interestingly, the ratings by the RAs were higher than those of the RNs. A suggested explanation was that, compared with the RNs, the RAs are more personally involved in the caring process. Similar findings were observed in a more recent study (Blomqvist & Hallberg 2001).

In contrast, the capability of carers to assess pain accurately in persons with dementia has been questioned (Cook *et al.* 1999). In a group of chronic care nursing home residents, there was a discrepancy between the nursing staff's evaluation of the residents' pain and the residents' evaluation of their own pain (Weiner *et al.* 1999). Unfortunately, although the level of cognitive functioning varied from normal to impaired, data analyses were performed over the whole group. One could speculate that the lower the level of cognitive functions, the higher the discrepancy in assessment between the two groups would be. People with mild to moderate cognitive impairment participated in the study of Engle *et al.* (2001). Licensed practical nurses and, to lesser extent, nursing assistants (NAs), underestimated the pain of these people. In another study, NAs overestimated the pain experienced by some of those with cognitive impairment (Horgas & Dunn 2001).

In summary, the results of several studies indicate a discrepancy between perceptions of pain by the residents with cognitive impairment and by their caregivers (Engle *et al.* 2001, Horgas & Dunn 2001). This is not illogical because there is now increasing evidence that at least some patients with AD might experience a decrease in pain (Scherder *et al.* 2001), whereas a subgroup of patients with vascular dementia might show enhanced pain perception (Scherder *et al.* 2003a,b). Knowledge about the relation between the type of dementia, its underlying neuropathology,

and pain could be of great value for the nurses who have to evaluate the residents' pain. Unfortunately, at least in the Netherlands, the education of NAs does not yet incorporate the latest insights into the complex relationship between subtypes of dementia and pain.

The study

Aim

The aim of the study was to compare the assessment by NAs of the pain experienced by patients with AD with the patients' own evaluation and to contribute to the knowledge of NAs about the influence of subtypes of dementia on experience of pain.

Design

A case-control study was performed in 2002/2003.

Participants

Participants were recruited from two Dutch nursing homes. The sample consisted of two groups: 20 patients with probable AD at stage 5 of the Global Deterioration Scale (Reisberg *et al.* 1982), and 17 older people without dementia. All patients with AD met the criteria of the National Institute of Neurological and Communicative Disorders and Stroke (NINCDS) and the Alzheimer's Disease and Related Disorders Association (ADRDA) for the clinical diagnosis of 'probable' AD (McKhann *et al.* 1984). Participants were excluded from participation if they had vision problems, a history of psychiatric disorder (particularly depression not related to dementia), alcoholism, cerebral trauma, cerebrovascular disease, hydrocephalus, neoplasm, epilepsy, disturbances of consciousness, or focal brain disorders.

This study, which deals in part with the assessment of pain during and after walking, necessitated that the participants had to suffer from chronic painful conditions, preferably in the lower extremities and the spinal column. Also the number of painful conditions within each participant was recorded. Within the AD group, 15 patients had one painful condition (e.g. arthrosis), five patients suffered from two painful conditions (e.g. osteoporosis in the spinal column plus arthrosis of the hip). In the non-demented group, 12 older people had one painful condition, whereas five participants suffered from two painful conditions. The number of painful conditions in the AD-group ($M = 1.25$) and in the non-demented group ($M = 1.29$) did not differ significantly ($\chi^2 = 0.09$, d.f. = 1, NS). No other chronic painful conditions

were present in the participants of both groups. All participants were able to walk, in most cases with a walking aid.

Pain assessment instruments

In order to assess pain, three visual analogue scales and one observation scale were administered. The visual analogue scales, initially developed for very young children who do not yet have fully developed memory and language capacities (Bieri *et al.* 1990, McGrath *et al.* 1996), were reliably administered in previous studies with patients with AD (Ferrell *et al.* 1990, Scherder & Bouma 2000, Scherder *et al.* 2001). The following scales were used.

Coloured Analogue Scale for the Assessment of Pain Intensity

The Coloured Analogue Scale (CAS) for the Assessment of Pain Intensity (McGrath *et al.* 1996) was designed to assess the intensity of pain, in a non-verbal way (Figure 1). This uses different colours and areas, which facilitate the participant's selection of a scale position that best reflects his pain intensity. Selecting the appropriate scale position is done by sliding

Figure 1 The Coloured Analogue Scale (CAS) to rate pain intensity. Left: front of the CAS as seen by the participants. Right: back of the CAS, which shows the numerical value of the rating. Reprinted from McGrath *et al.* (1996) with permission of Elsevier Science.

a horizontal marker from the bottom (no pain) to the top (maximum pain). The participant's score is the numerical value on the back of the scale that matches the selected scale position, with scores ranging from 0 to 100.

Coloured Analogue Scale for the Assessment of Pain Affect

The CAS for the Assessment of Pain Affect (McGrath *et al.* 1996) was used to assess the extent of suffering from the participant's own painful condition(s). The label 'no pain' at the bottom was replaced by the label 'no suffering', and the label 'maximum pain' at the top by the label 'a great deal of suffering'. Similar to the original CAS, each scale position referred to a number (a numerical value) on the back of the scale.

Faces Pain Scale

The Faces Pain Scale (FPS) (Bieri *et al.* 1990) measures the severity and affective components of pain and can be reliably and validly administered to children as young as 3 years of age (Figure 2). The FPS consists of line drawings of seven faces, that is, one neutral face and six faces that express increasing feelings of pain. Participants could rank their feelings from 'no pain' (score 0, the neutral face), to 'most severe pain' (score 6, the face expressing most feelings of pain), with the score ranging from 0 to 6.

Checklist of Non-verbal Pain Indicators

The Checklist of Non-verbal Pain Indicators (CNPI) (Feldt 2000) is an observational scale designed to measure verbal and non-verbal pain behaviours. The scale is scored while the participant is sitting quietly and during a walk. The checklist includes five non-verbal behaviours: (1) non-verbal vocalizations – moans; (2) grimacing – furrowed brow; (3) bracing – clutching; (4) restlessness – constant or intermittent shifting of position; (5) rubbing – massaging the affected area. In addition, verbal pain indicators were recorded, for example, 'that hurts'. Each pain indicator is scored with one point if present, and no points if not present (maximum score = 6).

Comprehension of the scales

For the CAS, respondents were asked to indicate at what level the marker should be positioned when a person had the most severe pain or suffered most from the pain (top of the scale) or had no pain at all or did not suffer at all (bottom of the

Figure 2 The Faces Pain Scale (FPS). Reprinted from Bieri *et al.* (1990) with permission from Elsevier Science.

scale). For the FPS, the participants had to indicate which face showed most pain and which face showed least pain.

Training of interviewers

The first author (EJAS) who has studied the influence of dementia on pain for a number of years using the same pain assessment instruments (visual analogue scales, observation scale; Scherder & Bouma 2000, Scherder *et al.* 2003b), instructed the second author (FJvM) intensively about the assessment procedures before the start of the study.

Data collection

Experience of pain by participants

The three visual analogue scales were administered before and after walking a short distance. During standing up, walking and sitting down, the investigator filled in the CNPI. All participants were asked to indicate the extent of their *present* pain.

Participants' pain assessed by nursing auxiliaries

The NA who had the closest relationship with the resident was asked to participate. The qualified NAs had trained for 3 years, during which time they had acquired specific nursing skills. Due to a shortage of staff, each resident has only one personal NA. All NAs fully understood the meaning of the scales. By means of the three visual analogue scales, the NAs were asked to indicate the present pain status of the participants before and after walking a short distance. The CNPI was not administered to the NAs.

Sequence of administration

To optimize objectivity, the sequence in which the participants and the NAs were approached with the scales was random: first the participant and subsequently the NA, and then in the reverse order.

Ethical considerations

The study was approved by a local ethics committee for patient-related scientific research. After the first global screening, the participants and their families/representatives were extensively informed about the purpose of the study and gave their written informed consent.

Data analysis

The main goal of the study was to examine the level of agreement between the pain perception of patients with AD, older patients without dementia and that of the NAs.

Although we have hypothesized that the NAs will overestimate pain in patients with AD, it is also possible that the NAs estimate the pain in some patients at a lower level. Therefore, first subtracting the scores of the NAs scores from those obtained from the participants (with and without dementia) and subsequently transforming negative scores into positive scores, we calculated absolute differences. Pain was assessed in two conditions using the same assessment method: at rest and after walking. Using the SPSS-PC program (Norusis 1992), analysis of variances (ANOVAs) and Mann-Whitney *U*-tests were used to assess NAs' estimation of participants' pain and the pain experience of participants themselves under each of these two separate conditions. In addition, chi-square tests and paired *t*-tests were used. Effect-sizes are presented as Cohen's *d*, where $d = 0.2$ is small, $d = 0.5$ is medium, and $d = 0.8$ is large (Cohen 1988).

Results

Demographics and level of cognitive functioning

Participants in the AD group and the non-demented group did not differ in age ($\chi^2 = 16.87$, d.f. = 16, NS) and education (Mann-Whitney *U*-test: $Z = 0.49$, NS; five categories: elementary school not finished: 1; elementary school: 2; lower secondary school: 3; higher secondary school: 4; higher vocational training for 18+/university: 5).

Level of cognitive functioning was assessed by means of the Mini-Mental State Examination (MMSE) (Folstein *et al.* 1975). Participants with a score between 15 and 25 were classified as having mild cognitive deterioration. A score of over 24 indicated normal cognitive functioning. The mean MMSE-score of the patients with AD and the older people without dementia differed significantly (Mann-Whitney *U*-test: $Z = 5.22$, $P < 0.000$) (Table 1).

Pain assessment

For each separate scale, the data will be presented as follows: (a) comprehension of the scale; (b) absolute differences in

Table 1 Demographics and level of cognitive functioning of patients with Alzheimer's disease and participants without dementia

Demographics and level of cognitive functioning	Patients with Alzheimer's disease	Participants without dementia
Age (years)	84.50 (74–98)	85.76 (72–93)
Education	2.55 (1–4)	2.76 (1–5)
MMSE	18.65 (12–24)	26.29 (25–30)

Values are given as mean (range). MMSE, Mini-Mental State Examination.

pain scores between participants and NAs, and (c) actual pain experience of the participants. Only those participants who understood the meaning of the scale were included in the analyses.

CAS for pain intensity

Comprehension of the scale. All older people without dementia understood the concept of the scale. Only one patient with AD (5%) failed to comprehend the meaning of the scale.

Absolute differences in pain scores between participants and NAs. Irrespective of rest or walking, ANOVA indicated that the absolute difference between the perception of pain by NAs and patients with AD was significantly larger than the absolute difference in pain scores between the NAs and those in the non-demented group. For means, standard deviations, ANOVA, and effect-size, see Table 2.

Within the AD group, paired *t*-tests further showed that the pain scores by the NAs were significantly higher than those of the patients with AD, both at rest [$t(18) = 2.56$; $P = 0.02$] and after walking [$t(17) = 3.33$; $P = 0.002$], implying that the NAs overestimated the patients' pain. At measurement time points, the pain evaluation by the NAs and the older people without dementia showed no significant difference: [$t(16) = 1.46$; NS] and [$t(15) = 1.11$; NS], respectively.

Actual pain experience of patients with AD vs. participants without dementia. Data analyses show that patients with AD experienced considerably less pain than the older people without dementia, both at rest and after walking. For means, standard deviations, and Mann-Whitney *U*-tests, see Table 3.

CAS for Pain Affect

Comprehension of the scale. All persons without dementia and all patients with AD fully understood the concept of the scale.

Absolute differences in pain scores between participants and NAs. Similar to CAS for Pain Intensity, ANOVA showed that the absolute difference between the perception of pain by patients with AD and NAs was significantly larger than the absolute difference in pain scores between the NAs and those people without dementia, irrespective of whether at rest or walking (see Table 2).

Also in line with the scores on CAS for Pain Intensity, paired samples *t*-tests indicated that within the AD group the NAs overestimated the patients' pain significantly both at rest [$t(19) = 2.69$; $P = 0.01$] and after walking [$t(18) = 2.71$; $P = 0.01$]. In contrast, in both conditions the pain evaluation by the NAs and the group of older people without dementia showed no significant difference [$t(16) = 0.83$; NS] and [$t(15) = 0.73$; NS], respectively.

Actual pain experience of patients with AD compared with older people without dementia. Analyses of the data obtained at rest and after walking indicate that, compared with the group without dementia, the reduction in pain experience in patients with AD was significant and showed a trend, respectively. For means, standard deviations, and Mann-Whitney *U*-tests, see Table 3.

Faces Pain Scale

Comprehension of the scale. Although one person of those without dementia misunderstood the concept of the scale (5.9%), only 13 of 20 AD patients (65%) actually understood the meaning of the FPS.

Table 2 Means, standard deviations, analyses of variance (ANOVA) and effect-sizes (*d*) of the absolute differences in pain scores between participants and nursing assistants (NAs)

Conditions of pain measurement	Pain scales	Differences NAs				Analyses of variance (ANOVA)			
		Persons without dementia		Patients with AD		<i>F</i>	d.f.	<i>P</i>	<i>d</i>
		Mean	SD	Mean	SD				
Pain at rest	CAS for Pain Intensity	23.97	27.03	41.71	22.53	6.72	1,34	0.007	0.89
	CAS for Pain Affect	18.53	16.80	40.50	32.45	6.33	1,35	0.009	0.80
	Faces Pain Scale	1.75	1.00	2.08	1.71	0.42	1,27	0.53	0.21
Pain after walking	CAS for Pain Intensity	27.03	20.36	41.94	28.00	3.08	1,32	0.04	0.55
	CAS for Pain Affect	21.72	18.09	44.32	34.52	5.55	1,33	0.01	0.86
	Faces Pain Scale	1.73	1.23	2.08	1.78	0.37	1,25	0.55	0.17

CAS, Coloured Analogue Scale; AD, Alzheimer's disease.

Table 3 Means and standard deviations of the actual pain experience as perceived by the participants (patients with AD and older people without dementia) and by the nursing assistants (NAs). Differences in actual pain experience between patients with AD and participants without dementia were analysed using Mann–Whitney *U*-tests

Conditions of pain measurement	Pain scales	People without dementia		NAs and people without dementia		Patients with AD		NAs and patients with AD		Mann–Whitney <i>U</i> -test patients with AD vs. people without dementia	
		Mean	SD	Mean	SD	Mean	SD	Mean	SD	Z	P
Pain at rest	CAS for Pain Intensity	31.32	32.39	41.47	29.13	16.05	24.92	40.39	26.89	1.56	0.06
	CAS for Pain Affect	28.82	31.74	33.82	26.71	14.38	23.21	41.38	33.33	1.64	0.05
	Faces Pain Scale	1.60	1.74	1.69	1.25	0.92	1.66	1.77	1.79	1.50	0.07
Pain after walking	CAS for Pain Intensity	30.31	33.77	39.53	28.33	12.78	22.29	44.17	28.05	1.78	0.04
	CAS for Pain Affect	25.16	28.89	30.31	23.82	13.29	23.54	43.18	34.64	1.57	0.06
	Faces Pain Scale	1.53	1.69	1.87	1.46	0.75	1.60	1.54	1.76	1.59	0.06
	CNPI	0.81	1.17			0.88	1.31				

CAS, Coloured Analogue Scale; CNPI, Checklist of Non-verbal Pain Indicators.

Absolute differences in pain scores between participants and NAs. Analyses of variance showed that the absolute difference in pain evaluation between the NAs and the patients was neither significantly higher nor significantly lower than the difference in pain evaluation between that of the NAs and those people without dementia, both at rest and after walking. For means, standard deviations, ANOVA, and effect-sizes, see Table 2.

Actual pain experience of patients with AD vs. participants without dementia. With respect to the pain measurements at rest and after walking, the lower scores on this scale by the patients with AD in comparison with the older people without dementia showed a trend. For means, standard deviations, and Mann–Whitney *U*-tests, see Table 3.

Checklist for Non-verbal Pain Indicators

Actual pain experience of patients with AD vs. participants without dementia. Data analyses indicated that the group with AD and the group without dementia did not show a significant difference in scores on the CNPI. For means, standard deviations and Mann–Whitney *U*-tests, see Table 3.

Discussion

Comprehension of the various scales

CAS. The results show that none of the participants without dementia and only one patient with AD misinterpreted the CAS for Pain Intensity. None of the participants failed to understand the proper meaning of the CAS for Pain Affect.

FPS. Seven of 20 patients with AD misinterpreted the purpose of the scale. In the group without dementia, the proper meaning of the scale was unclear for only one person. These results are quite similar to those observed in earlier studies (Scherder & Bouma 2000, Scherder *et al.* 2001).

Absolute differences in pain scores between participants and NAs

CAS for Pain Intensity and Pain Affect. Both at rest and after walking, the absolute difference in pain scores between the NAs and the participants in the non-demented group was much smaller than the difference in pain evaluation between the NAs and the patients with AD.

FPS. Although the difference in pain perception between the NAs and the participants was somewhat smaller in the group without dementia than in the group with AD, this difference was not significant. The scores on the FPS have a smaller range (0–6) than the CAS scales (0–100) and may therefore be less capable of measuring more subtle differences in pain evaluation.

Importantly, particularly the difference in pain scores on both the CAS scales and, to a lesser degree, the difference in scores on the FPS between the NAs and the patients with AD confirm our hypothesis that NAs overestimated the pain experience in the group with AD (Table 2). It is notable that the difference between estimations by NAs and patients with AD with respect to pain at rest, measured using both the CAS for Pain Intensity and Pain Affect, showed a large effect size. Considering pain after walking, the difference in estimations

What is already known about this topic

- Pain assessment in cognitively impaired older people is complex.
- Older persons with dementia use fewer analgesics than older persons without dementia.
- Without further specification of the diagnosis, nursing assistants may either underestimate or overestimate the pain in 'cognitively impaired older people'.

What this paper adds

- Patients with Alzheimer's disease may experience less pain than older people without dementia.
- Lack of knowledge about the influence of subtypes of dementia on pain may hinder the nursing assistants in assessing pain in a reliable way.
- Nursing assistants should be kept informed of recent knowledge developments in this area.

between the NAs and the patients with AD in scores on the CAS for Pain Intensity again had a large effect size, whereas a medium effect size was noted when the CAS for Pain Affect was used. In a previous study (Horgas & Dunn 2001), the overestimation of pain by the NAs was explained by their need to show that patients are adequately cared for in a nursing home setting. However, an overestimation of pain might lead to an excess of analgesic prescription, risking possibly harmful side-effects and causing unnecessary costs for the healthcare system.

Better education and thus knowledge about the relation between subtypes of dementia and its underlying neuro-pathology would contribute greatly to the reliability of pain assessment (Scherder *et al.* 2003a) and consequently to pain treatment (Horgas & Dunn 2001); for example, atrophy of areas such as the hippocampus may cause a decrease in affective pain processing, whereas white matter lesions may provoke an increase in pain (Scherder *et al.* 2003a).

Actual pain experience of patients with AD vs. participants without dementia

CAS for Pain Intensity, CAS for Pain Affect, and the FPS. The results show that, irrespective of whether at rest or walking, the patients with AD in the present study indicated that they experienced less pain intensity and suffered less from pain than older people without dementia.

Although we had similar findings in earlier studies (Scherder & Bouma 2000, Scherder *et al.* 2001), great caution should be exercised in generalizing these findings to all patients with AD.

CNPI. The finding that there was no difference in scores between both groups might be caused by the fact that the items of the CNPI reflect rather high levels of pain intensity, such as groans, grimacing, or cursing during movement. The highest level of pain intensity – in the present study indicated by the group of older people without dementia – was only moderate (Table 2).

Study limitations

First, despite the fact that pain assessment occurred at rest and after walking, it took place at only one specific moment. Secondly, each resident has only one NA who knows the mental and physical condition of the resident the best. Consequently, interrater reliability could not be calculated. Furthermore, as the NAs estimated the pain of the patients with AD to be as high as the pain of the participants without dementia, it would be interesting in future research to consider the amount of pain medication required in relationship to the NAs' opinions. Finally, it is unclear whether the apparent diminished pain experience in patients with AD can be generalized to other types of dementia. In future research about pain assessment and dementia, it is therefore important to differentiate between the particular types of dementia.

Conclusion

The observed overestimation by NAs of patients' pain might specifically be related to AD, because AD is characterized by a decrease in the pain experience. In contrast, patients with vascular dementia show, in general, an increase in pain experienced and new studies are needed to examine whether NAs may underestimate that pain. The capacity of NAs to assess pain in other subtypes of dementia, such as fronto-temporal dementia and Lewy body disease, has not so far been examined, and we are only at the beginning of a new and intriguing research episode focused on pain management in dementia.

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Author contributions

EJAS and FVM conceived and designed the study, performed the data collection and analysis and provided statistical expertise. EJAS was responsible for drafting the manuscript, making critical revisions, obtaining funding, supervising, and administrative support.

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