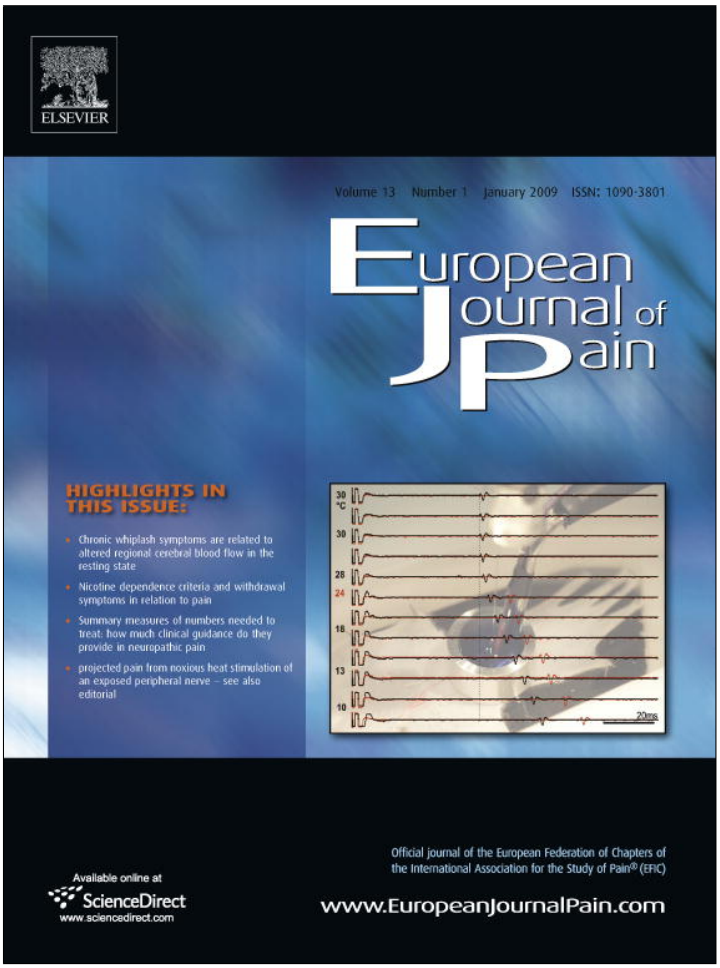

European Journal of Pain 13 (2009) 89–93

Contents lists available at ScienceDirect

European Journal of Pain

journal homepage: www.EuropeanJournalPain.com

The prevalence of pain in nursing home residents with dementia measured using an observational pain scale

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ARTICLE INFO

Article history:
Received 20 June 2007
Received in revised form 13 February 2008
Accepted 27 February 2008
Available online 16 May 2008

Keywords:
Pain
Prevalence
Nursing home
Elderly
Assessment

ABSTRACT

Background: Studies on pain and pain prevalence in older people with dementia are limited compared to those on cognitively intact older people. Pain prevalence rates in older people with dementia are estimated to be between 28% and 83%.

Aims: This study aimed to explore pain prevalence in nursing home residents with dementia using observational scale PACSLAC-D, and to identify the association between pain prevalence and (dementia) demographic parameters such as cognitive status, gender, analgesic use and co-morbidity.

Methods: Using an observational study design, 117 residents were observed and assessed for pain during personal morning care. Prevalence data were calculated and regression analyses applied.

Results: This study showed that almost half of the participants (47%) experienced pain to some extent. However, overall pain intensity scores were relatively mild. Among the independent variables, co-morbidities, analgesic use and the adjusted interaction term 'co-morbidities + analgesic use' had the strongest associations with pain and were thus shown to be valid significant predictors.

Conclusion: With its relatively new approach of measuring pain using an observational scale, this study confirms the expectation gleaned from other studies on less impaired older populations: namely, that pain prevalence in older residents with dementia in Dutch nursing homes is high.

1. Introduction

Pain represents a major problem with serious consequences for a patient's quality of life (Herr and Mobily, 1991). Pain prevalence rates in older people with dementia vary enormously, from 28% to 83% (e.g. Ferrell et al., 1995; Lin et al., 2006; McClean and Higginbotham, 2002; Parmelee et al., 1993; Sengstaken and King, 1993; Wagner et al., 1997; Weiner et al., 1999). These varying rates reflect the use of less reliable and valid approaches, which include:

(1) clinical or medical record diagnoses to gather data in order to estimate the pain prevalence (Jones et al., 2005; Sengstaken and King, 1993);
(2) the residents assessment instrument (RAI), minimum data set (MDS) items on pain (e.g. Lin et al., 2006; Sawyer et al., 2007; Zyczkowska et al., 2007); and
(3) the self-reporting of pain, often viewed as the 'gold standard'. Although self-report might be the most accurate way of measuring pain prevalence in residents with mild dementia, it implies that a subset of older residents with moderate to severe dementia is either not reliably assessed or excluded altogether.

Thus, given the different methods used and variable study populations, estimated pain prevalence rates should be interpreted with care.

It is evident that there is a need for a valid and reliable tool to measure pain prevalence in nursing home residents with (severe) dementia. The Dutch version of the pain assessment checklist for seniors with limited ability to communicate (PACSLAC-D) (Zwakhalen et al., 2007), based on the PACSLAC (Fuchs-Lacelle and Hadjistavropoulos, 2004), is a reliable, valid and useful observational scale to assess pain in residents with dementia. Indeed, the PACSLAC was evaluated as one of the best scales currently available (Zwakhalen et al., 2006). As yet, however, prevalence rates have not been determined by way of observational scales.

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1090-3801/$34.00
doi:10.1016/j.ejpain.2008.02.009

The same holds true for associations between pain and type of dementia, and demographic characteristics such as cognitive status, gender, analgesic use and co-morbidity. Residents who received multiple medications were found to have greater degrees of pain (Sawyer et al., 2007); pain prevalence appears to be demonstrably higher among women than men (McClean and Higginbotham, 2002; Sawyer et al., 2007) and lower among residents with higher levels of cognitive impairment (Proctor and Hirdes, 2001). On the other hand, other studies (Fisher et al., 2002; Leong and Nuo, 2007) have concluded that cognitive status does not affect pain prevalence. Gruber-Baldini et al. (2005) and Smalbrugge et al. (2007) found associations between depression and pain, and there is evidence that pain tolerance differs in people with Alzheimer's disease (Benedetti et al., 1999; Scherder et al., 1999). However, more research is needed.

The aim of this study is to explore pain prevalence in nursing home residents with dementia as measured by the PACSLAC-D, and to identify the association of such pain with residents' characteristics.

2. Methods

2.1. Design

An observational study design was used to gather data pertaining to the research questions.

2.2. Sample

All residents of three Dutch nursing home dementia special care units, one located in Nijmegen (two units), one in Maastricht (four units) and one in Landgraaf (four units) were invited to enter the study. Residents were included if (1) they met DSM-IV criteria for dementia (American Psychiatric Association, 1994); (2) they had been institutionalised for at least four weeks prior to the data collection; (3) they were at least 60-years-old; (4) they had not undergone major environmental changes in the month prior; and (5) their legal guardians had given written informed consent.

2.3. Measurement and residents' characteristics

Pain was assessed using the Dutch version of the pain assessment checklist for seniors with limited ability to communicate (PACSLAC-D). Developed by Fuchs-Lacelle and Hadjistavropoulos (2004), PACSLAC is a dichotomous 60-item observational scale developed to assess pain in older residents with dementia. The PACSLAC-D is a brief, revised version of 24 items covering three subscales: facial and vocal expression, resistance/defence and social-emotional aspects/mood. The factor structure of the revised Dutch scale was established using principal component analysis. The PACSLAC-D demonstrated high validity (Zwakhalen et al., 2006) and internal consistency for both the complete scale (alpha 0.82–0.86) and for all subscales (alpha 0.72–0.82) (Zwakhalen et al., 2007). A score of at least 4 out of 24 (the maximum pain score) is considered to indicate the presence of pain. With a cut-off score of $\geqslant 4$ the sensitivity of the PACSLAC-D is 0.96 and specificity 0.90. A step-by-step approach was conducted to determine these cut-off scores. First, global cut-off scores were determined by comparing linear transformation using other observational scales for non-verbal populations with known cut-off scores for pain (e.g. DOLOPLUS, KIDPAINS). This linear transformation was therefore used as an external criterion. Subsequently, an empirical approach was used to verify the cut-off point determined in the first phase. This cut-off point was certified using data from a previous study (Zwakhalen et al., 2006). Based on this study, sensitivity and specificity were established.

To re-examine the inter-rater reliability of the PACSLAC-D in the present study, fifteen residents were assessed by two raters simultaneously during morning care. To synthesise the results, the two-way random absolute agreement method was used to examine the inter-rater reliability, which compensates for an extra source of variance due to differences between raters. Intra class correlation (ICC) was found to be high for the total scale 0.89; adequate for the subscales of facial and vocal expression (ICC = 0.89) and resistance/defence (ICC = 0.76); and moderate for the subscale social-emotional aspects/mood (ICC = 0.56).

Demographic information (age, gender) was gathered from all participants and recorded on a datasheet. Information about the type of dementia was obtained from patients' medical records. Co-morbidities were recorded from residents' medical records and classified according to the classification of diseases in nursing home patients (CvZ-V) (Sig Zorginformatie en de Nederlandse Vereniging van Verpleeghuisartsen (NVVA), 1995), compatible with the international classification of diseases, version 10 (ICD-10) (http://www.who.int/classifications/icd/en/). Also, 'depressive symptoms' were registered if mentioned as present in the resident's medical record. Prescribed medication use (analgesics and psychotropics) were registered and classified according to the anatomical therapeutic chemical (ATC) classification system (World Health Organization Collaborating Centre for Drug Statistics Methodology, 1997). The cognitive status of all residents was evaluated using the standardised mini-mental state examination (MMSE) (Folstein et al., 1975). This test (ranges: 0–30 points) was designed for and is widely used to briefly screen for cognitive impairment in older adults.

2.4. Pain ratings

Two weeks prior to data collection, the ten raters of the three participating nursing homes received a short instruction session of approximately 30 min on how to use the PACSLAC-D. Mostly female ($n = 6$), they ranged from 23 to 48 years (mean = 36.2: SD = 7.2). The mean number of years of experience was 15.4 (SD = 8.1). The majority (70%, $n = 7$) were certified caregivers and two (20%) were registered nurses (RNs).

Residents were observed once for five randomly selected minutes during personal morning care (e.g. washing, showering). Morning care was chosen as the observational moment because it is believed to be a provocative time for pain. After observation, the PACSLAC-D was scored immediately. Additional comments from the PACSLAC-D checklist could be made on the first page (such as 'pain medication was distributed prior to observational moment'). Demographics and information on medication use and co-morbidity were gathered by a research assistant after residents were observed to ensure that nurses were unaware of this information and, therefore, that it would not influence scoring procedures. No observers (except for the two RNs) had prior in-depth knowledge of the nursing home residents; rather, they observed residents of a ward they were unfamiliar with.

2.5. Ethical considerations

Ethical approval was obtained from the Medical Ethics Committee (in the Arnhem–Nijmegen region in the Netherlands; #2006/068). Permission to conduct the study was also obtained from the managing directors of the nursing homes. Before participation, registered legal guardians of the residents provided written informed consent.

2.6. Data analyses

Descriptive statistics were computed for the respondents' characteristics and in relation to pain. Differences between

groups were determined using a *t*-test and prevalence data calculated.

At first, a multiple linear regression model was tested with pain as the outcome variable, and the predictors of gender, number of co-morbidities, use of analgesics (dichotomised), use of psychotropics (dichotomised), depressive symptoms (dichotomised), type of dementia (vascular dementia versus Alzheimer's) and total MMSE score as independent variables. The starting model included the interaction term 'co-morbidities + analgesic use', which was tested and found to be significant. In this multiple regression model the explained variance (R^2) was described. Because data were positively skewed, they were transformed using a log transformation.

In addition, a logistic regression model was tested by dichotomising the outcome pain/no pain on the PACSLAC-D (cut-off score: pain $\geqslant 4$). Statistical analyses were performed using SPSS software; results were considered statistically significant if *p*-values were less than 0.05.

3. Results

3.1. Sample

Of the 179 nursing home residents invited to participate, 117 gave permission and met the inclusion criteria; 20% were men ($n = 23$) and 80% women ($n = 94$). Ages ranged from 60 to 97, with a mean of 82.8 (SD = 6.1). The type of dementia as well as the severity of the impairment varied. The participants' mean MMSE score was 5.7 (SD = 6.8), indicating that the majority of the residents were severely cognitively impaired. They had on average 4.2 (SD = 1.9) co-morbid conditions. Table 1 presents further information on the residents' characteristics.

Table 1
Descriptive information of the nursing home residents included in the study

Characteristics of PG residents (n = 117)		
Male/female		23/94
Age in years (SD)		82.8 (6.1)
Severity of the impairment based on the MMSE n = (%)		
MMSE $\geqslant$ 24		1 (0.9%)
Mild-moderate, MMSE $\geqslant$ 8 < 24		39 (33.3%)
Severe, MMSE $\leqslant$ 7		68 (58.1%)
Not applicable (missing)		9 (7.7%)
Dementia diagnosis n = (%)		
Alzheimer's disease		41 (35.1%)
Vascular dementia		31 (26.5%)
Other (e.g. parkinson's disease, frontal lobe)		10 (8.4%)
Mixed (Alzheimer's/vascular)		15 (12.9%)
Unknown		20 (17.1%)
Medication (analgesic and psychotropic) n = (%)		
Analgesic	None	63 (53.8%)
	Regular	37 (31.6%)[a]
	When necessary	8 (6.8%)
	Daily and when necessary	9 (7.7%)
Psychotropic	None	34 (29.1%)
	Regular	52 (44.4%)
	When necessary	6 (5.1%)
	Daily and when necessary	25 (21.4)
Total amount of different psychotropics per patient per day	1	41 (49.4%)
	2	29 (34.9%)
	3	9 (10.8%)
	4	4 (4.2%)
Depressive symptoms	Yes	95 (81.2%)
	No	22 (18.8%)

[a] The use of acetylsalicylic acid is not included in the total use of analgesic otherwise total regular use would become 47% instead of 31.6%, this medication is frequently used in long term low doses to prevent cardio vascular diseases.

3.2. Pain prevalence and characteristics of residents in pain

Of the 117 residents, 47% ($n = 55$) had a PACSLAC-D score greater than or equal to 4, indicating possible pain. Prevalence rates differed slightly between the three participating nursing homes: 41%, 48% and 52%.

The mean pain score of the 55 residents who experienced pain was 6.31 (SD = 2.8; ranges 4–13) with a median of 5. Further investigation of the data showed that 40% of the residents who experienced pain received no pain medication. The overall mean pain score for the total group measured by the PACSLAC-D was 3.6 (SD = 3.2; ranges 0–13).

Of these 55 residents who registered pain (PACSLAC $\geqslant 4$), all tended to be more severely cognitively impaired. Some 67% of the residents ($n = 37$) had an MMSE score below 7, indicating severe cognitive impairment as compared to 50% ($n = 31$) of the non-pain residents.

Residents with pain did not have significantly more additional diagnoses (mean number of co-morbidities = 4.4) as compared to those with no pain (mean number of co-morbidities = 4.1).

There seems to be a difference in PACSLAC-D scores between Alzheimer's residents ($n = 41$) and residents with vascular dementia ($n = 31$). Although not significant ($p = 0.2$), slightly higher PACSLAC-D scores (mean = 4.2; SD = 3.5) were determined for the Alzheimer's group as compared to the residents with vascular dementia (mean = 3.3; SD = 2.7).

3.3. Predictors associated with pain

The multiple linear regression analyses showed that gender ($p = 0.03$), co-morbidities ($p < 0.001$), use of analgesics ($p < 0.01$) and the interaction term 'co-morbidities + analgesic use' ($p < 0.001$) were significantly related to pain as measured on the PACSLAC-D. See Table 2 for the final linear regression model.

The regression analyses demonstrated that women were at higher risk of pain than men ($p = 0.03$). Residents with more health problems or who received analgesics on a regular basis had a higher chance of pain. The variables (use of psychotropics, total MMSE score) did not contribute significantly to explaining variance. The overall $R^2 = 0.150$ indicates that predictors account for 15% of pain variance.

In addition, to confirm our findings we used logistic regression by dichotomising the outcome pain/no-pain on the PACSLAC-D (cut-off score: pain $\geqslant 4$). The results of the logistic regression were similar to those of the linear regression with the exception of the variable gender, which was not found to be significantly associated with pain in the logistic regression. The association remained significant for the variables, co-morbidities ($p < 0.01$; OR 1.74; 95% CI 1.15–2.62) and interaction term ($p < 0.01$; OR 0.48, 95% CI 0.29–0.79). In particular, the logistic regression demonstrated that

Table 2
Summary of results of linear regression model: characteristics associated with pain

Predictor	B	Standard error	Significance	Standard B	95% CI	
Final linear model $R^2 = 0.150$						
Gender (women = 0, men = 1)	−0.16	0.07	0.03	−0.19	−0.30	−0.01
Co-morbidities	0.09	0.02	<0.001	0.54	0.04	0.14
Use of analgesics	0.40	0.14	<0.01	0.60	0.13	0.67
Co-morbidities + analgesics	−0.10	0.03	<0.001	−0.86	−0.17	−0.04

Note: 95% CI = 95% confidence interval.

residents who used analgesics were more likely to have pain (OR 14.94; 95% CI 1.88–119.06).

Since no objective assessment tool was used to measure depressive symptoms and since data were more explorative on this variable, it was not included in the primary regression analyses. When we additionally performed a linear regression analysis including this variable (depressive symptoms yes/no), it proved to be a weak association for the presence of pain ($p = 0.05$). The logistic regression showed that the 'depressive symptoms' variable was not significant.

The demographic information in Table 1 shows that the dementia type was unknown for 17% of the residents – this is because we depended on medical records for this information. Furthermore, a considerable number (21%) of residents displayed a wide variety of dementia types (e.g. Parkinson's, mixed type, frontal lobe). Due to these missing data and heterogeneity, dementia type was not included in the primary regression analyses. However, in a subsequent linear and logistic regression analysis, this variable (type of dementia: vascular/Alzheimer's) was also added. Analysis showed that dementia type did not contribute significantly to explaining variance ($p > 0.2$).

4. Discussion

This study confirms what we expected from other studies on populations with less impaired older residents; namely, that pain prevalence in older residents with dementia living in Dutch nursing homes is high. Almost one out of two residents is possibly in pain, as assessed with a PACSLAC-D score greater than or equal to 4. However, it must be noted that the overall scores of residents who experienced pain during morning care were 'mild' to 'moderate' (median = 5). Furthermore, this study shows number of co-morbidities, the use of analgesics and the interaction term 'co-morbidities + analgesic use' as most strongly associated with pain prevalence.

Although some studies (e.g. Ferrell et al., 1995; Lin et al., 2006) determined the pain prevalence in older residents with dementia by using the MDS or patients' self-reports, to the best of our knowledge only one other study has used an observational tool specially developed for this target population. Leong and Nuo's (2007) recently published study used the PAINAD with a sample of 36 severely impaired residents to determine pain prevalence rates. They found that pain was present in approximately 44% of the residents. However, because the PAINAD, a five-item observational tool, was scored retrospectively by asking the nurses if they had noticed any of the specified behaviours during the previous week, their rates are only comparable to some degree with those found in our study. In accordance with our findings, though, they did find a high proportion of residents with mild pain (33%).

The associated pain factors in our study were gender, number of co-morbidities, and analgesic use. The linear regression showed that women were more at risk for pain than men. This is consistent with other international studies (Brattberg et al., 1996; Crook et al., 1984; Elliott et al., 1999; Magni et al., 1993); however, it should be mentioned that in our study gender was not found to be statistically significant – it had only a weak association ($p = 0.03$) in the linear regression and was not a significant predictor in the logistic regression.

The OR related to analgesic use was found to be high (OR 14.94). Patients who received analgesics were almost 15 times more likely to have pain. This finding confirms that even treated residents clearly do not receive adequate treatment, since analgesic use was found to be the strongest predictor of pain presence. Pain management by way of complete relief is obviously very difficult; the use of a pain scale provides the opportunity to register and re-evaluate the scores after an intervention such as analgesic use. On the other hand, this result (high OR related to analgesic use) could also be interpreted as validity support of the PACSLAC-D, since the scale seems to be especially useful for detecting those who are at high risk for pain.

Our findings show that the level of cognition as measured by the MMSE seems to be associated with the presence of pain. Fisher et al. (2002) found similar results, although they excluded severely impaired older residents. Leong and Nuo (2007) also found that pain prevalence did not differ among residents with normal, mildly impaired or severely impaired cognition. In contrast, other studies did find a significant association between cognition and pain (e.g. Parmelee et al., 1993).

In previous studies depression was shown to relate to pain in cognitively impaired and non-impaired populations (Gruber-Baldini et al., 2005; Landi et al., 2005; Leong and Nuo, 2007; Magni et al., 1993; Sawyer et al., 2007; Smalbrugge et al., 2007). In our study, depression was not optimally assessed because it was not one of the main outcome measures. When 'depressive symptoms' was added as an independent variable, it proved to have a weak association for the presence of pain.

The literature suggests that residents with Alzheimer's dementia experience a decrease in pain (Benedetti et al., 1999; Scherder et al., 2001). In contrast, descriptive statistics in this study demonstrated that the PACSLAC scores of residents with Alzheimer's dementia (mean = 4.2; SD = 3.5) were slightly (but not significantly) higher than those of residents with vascular dementia (mean = 3.3; SD = 2.7). However, the results of the regression analysis showed that dementia type did not contribute significantly to explaining variance.

These results should be interpreted in the context of some limitations, including a relatively small sample size ($n = 71$). However, there is no reason to doubt that the results are representative since, with respect to most variables (with the exception of the use of psychotropics and analgesics), subjects did not differ between nursing homes. Yet, to allow for generalisation and to avoid over- or underestimation of pain, a larger study on pain prevalence is clearly warranted in the near future. We would recommend using another staging instrument in addition to the MMSE in order to classify the stage of dementia – for example, the global deterioration scale (GDS) (Reisberg et al., 1988). The MMSE used in the present study is a relatively cruder instrument, initially developed for screening.

In previous studies (Cohen-Mansfield and Lipson, 2008; Pautex et al., 2005; Zwakhalen et al., 2006), residents (mostly mildly and moderately impaired) were asked to score a self-report scale (e.g. verbal rating scale). In the present study, patients' self-reports were not included, a factor which might have strengthened the methodology. This could also hold for the fact that we used a 'one-point' measurement approach. Methodologically speaking, it would have been ideal to measure pain prevalence over several consecutive days, but this was not possible in light of practical limitations; thus, a one-time measurement approach was chosen with the same rater per ward.

In the present study, the inter-rater reliability of the PACSLAC-D was re-examined by assessing fifteen residents simultaneously by two raters. Although the intra class correlation (ICC) was found to be high for the total scale 0.89 and adequate for almost all the subscales, that only two raters assessed the inter-rater reliability should be seen as a limitation of this study. However, in an earlier study the inter-rater reliability of the PACSLAC between all scoring pairs ($n = 12$) was addressed and ranged from 0.39 to 0.97 (Zwakhalen et al., 2006).

Furthermore, residents were assessed during five randomly selected minutes of morning care, thought to be a provocative moment for pain. This approach was chosen because of the large variability of time spent on personal morning care such as washing and bathing. By randomly selecting five-minute intervals, observational procedures were standardised for all participants. However, the time factor may have fluctuated as far as content was concerned due to this standardisation. In addition, the selection of moments could lead to the under-diagnosing of pain. Thus it should be acknowledged that this approach has its limitations and might have influenced findings to some extent.

5. Conclusion

Overall pain intensity scores were relatively mild, but almost half the participants experienced pain to some extent. Among the independent variables, co-morbidities, analgesic use and the adjusted interaction term 'co-morbidities + analgesic use' were shown to be significant factors with strongest associations with pain.

Widespread implementation of observational pain scales such as the PACSLAC-D should help healthcare workers recognise and evaluate pain cues in a more reliable, valid and simple manner. Although the use of a proper pain scale in a non-verbally communicating population is just one aspect of adequate pain assessment and management, it could certainly increase nurses' awareness and stimulate them to take the process of pain management one step closer to a pain-free nursing home.

Acknowledgement

The authors would like to thank the staff of the participating nursing homes for their collaboration.

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