

Pain, agitation, and behavioural problems in people with dementia admitted to general hospital wards: a longitudinal cohort study

Elizabeth L. Sampson^{a,b,*}, Nicola White^a, Kathryn Lord^a, Baptiste Leurent^a, Victoria Vickerstaff^a, Sharon Scott^a, Louise Jones^a

Abstract

Pain is underdetected and undertreated in people with dementia. We aimed to investigate the prevalence of pain in people with dementia admitted to general hospitals and explore the association between pain and behavioural and psychiatric symptoms of dementia (BPSD). We conducted a longitudinal cohort study of 230 people, aged above 70, with dementia and unplanned medical admissions to 2 UK hospitals. Participants were assessed at baseline and every 4 days for self-reported pain (yes/no question and FACES scale) and observed pain (Pain Assessment in Advanced Dementia scale [PAINAD]) at movement and at rest, for agitation (Cohen–Mansfield Agitating Inventory [CMAI]) and BPSD (Behavioural Pathology in Alzheimer Disease Scale [BEHAVE-AD]). On admission, 27% of participants self-reported pain rising to 39% on at least 1 occasion during admission. Half of them were able to complete the FACES scale, this proportion decreasing with more severe dementia. Using the PAINAD, 19% had pain at rest and 57% had pain on movement on at least 1 occasion (in 16%, this was persistent throughout the admission). In controlled analyses, pain was not associated with CMAI scores but was strongly associated with total BEHAVE-AD scores, both when pain was assessed on movement ($\beta = 0.20$, 95% confidence interval [CI] = 0.07–0.32, $P = 0.002$) and at rest ($\beta = 0.41$, 95% CI = 0.14–0.69, $P = 0.003$). The association was the strongest for aggression and anxiety. Pain was common in people with dementia admitted to the acute hospital and associated with BPSD. Improved pain management may reduce distressing behaviours and improve the quality of hospital care for people with dementia.

Keywords: Pain, Dementia, Behavioural problems, Agitation, General hospital

1. Introduction

Pain is commonly underdetected and undertreated in people with dementia^{20,34,47} who may be unable to understand³⁷ or verbalise⁴⁴ that they are in pain. Previous studies have focussed on community samples and care home residents^{49,54} and have found that pain affects up to half of people with dementia in these settings.^{48,52} Little attention has been given to pain in people with dementia in the general hospital, despite the fact that dementia is common in older hospital inpatients, with a prevalence on medical wards of around 40%.^{33,42} Identifying pain in people with dementia is vital because poor pain recognition and management slows recovery, increases functional decline, and may be associated with behavioural and psychiatric symptoms of dementia (BPSD).^{22,44}

Sponsorships or competing interests that may be relevant to content are disclosed at the end of this article.

^a Marie Curie Palliative Care Research Department, Division of Psychiatry, University College London, W1W 7EJ, United Kingdom, ^b Barnet Enfield and Haringey Mental Health Trust Liaison Team, North Middlesex University Hospital, London, N18 1QX, United Kingdom

*Corresponding author. Address: Marie Curie Palliative Care Research Department, Division of Psychiatry, University College London, 67-71 Riding House St, London, W1W 7EJ, United Kingdom. Tel.: +44 (0) 207 679 9730; fax: +44 (0) 20 7679 9426. E-mail address: e.sampson@ucl.ac.uk (E. L. Sampson).

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These symptoms are common and affect up to 85% of people with dementia over a 5-year period.⁵¹ They comprise a range of problems including agitation, psychotic symptoms (hallucinations and delusions), wandering, aggression, mood disturbance, and apathy. Agitation is a particularly distressing symptom, which has been defined as “inappropriate verbal, vocal, or motor activity that is not judged by an outside observer to result directly from the need or confusion of the individual”¹¹ and includes behaviours such as screaming, hitting, and pacing. However, causes of BPSD are often complex, multifactorial, and associated with genetic factors, neurodegenerative changes, and unmet needs, such as unrecognized pain.³¹ Psychiatric symptoms of dementia significantly increase costs of care,³⁶ decrease quality of life of the person with dementia,²¹ and increase caregiver burden and depression.⁹

A number of recent studies have examined the association between pain and BPSD.^{22,26,54} When in pain, a person with dementia may respond with agitation, resistiveness to care, depression, or withdrawal.^{41,54} This association is, however, complex. Some observational pain scales are sensitive in detecting pain in people with dementia but have a high false-positive rate and may actually detect changes in behaviour caused by fear, frustration, or anger.²⁸ In the general hospital, other factors such as delirium and the confusing ward environment may increase the risk of BPSD occurring² and make the detection and management of pain more challenging.

It is not clear whether particular types of BPSD are more likely to be associated with pain in the general hospital setting. Studies conducted in care homes have found socially inappropriate

behaviour, resisting care, delusions, and reduced wandering are significantly associated,⁵⁴ whereas others have identified aggression and agitation as being strongly associated with pain.¹ A first step in improving the identification and management of pain in people with dementia in general hospitals is to identify its prevalence and understand the key clinical and behavioural associations.

Our aim was to define the prevalence of pain using self-rated and observational pain scales in people with dementia in the general hospital. We also wished to examine demographic and clinical factors associated with pain in this population and to explore a hypothesised association between pain and BPSD, including agitation in this setting.

2. Methods

This longitudinal cohort study was conducted in 2 large acute general hospitals in London, United Kingdom. Both cover a wide area encompassing socioeconomic and ethnic diversity, serving a combined population of 2 million people.

2.1. Participants

Two research assistants spent 5 months at each site (4th April 2011 until 6th March 2012), assessing within 72 hours of admission, all patients admitted with any type of medical problem under the care of geriatricians. Clinical staff identified patients who met the inclusion criteria:

- (1) Age 70 years or above with an unplanned acute medical admission
- (2) Able to give written informed consent or with an informal carer or “professional consultee” available to give agreement for the person to participate
- (3) Abbreviated Mental Test Score (AMTS¹⁹) of $\leq 7/10$ (routinely measured on admission).

We excluded patients who indicated verbally or nonverbally that they did not wish to participate, were moribund, or non-English speaking.

Potential participants were screened for delirium using the Confusion Assessment Method (CAM).²⁵ Those who were not delirious were consented or agreement was obtained from a carer and assessed using the Mini Mental State Examination (MMSE).¹⁶ If they scored ≤ 24 , they entered the study. Patients with initial delirium were rescreened 48 hours later, if this resolved, we completed the MMSE. If delirium was persistent, patients were ineligible as we could not establish a clear dementia diagnosis. However, those with delirium who already had a documented specialist dementia diagnosis (neurology, geriatrics, old age psychiatry) were eligible. Dementia diagnosis was confirmed using a structured clinical assessment based on operationalised DSM-IV criteria,³ comprising cognitive testing (MMSE), structured notes review, and discussion with family and the clinical team.

2.2. Study measures

Dementia severity was measured using the Functional Assessment Staging Scale (FAST).³⁹ Presenting medical problem at admission, Charlson Co-morbidity Score,⁷ Waterlow score,⁵⁷ and demographics were obtained from medical notes. Drug charts were examined at baseline and at every study visit for the prescription of analgesics, we documented the type of drug and whether it was prescribed on a regular or “as-required” basis.

The Pain Assessment in Advanced Dementia scale (PAINAD) was rated first.⁵⁶ This observational tool comprises 5 domains

(breathing, negative vocalisations, facial expression, body language, and consolability) each scored by severity from 0 to 2 points (maximum 10). Pain was observed during movement (care task such as repositioning in bed or standing from chair) and at rest. Assessors received training in the use of all tools and interrater reliability for the PAINAD for 35 random cases at rest ranged from 94.3% to 100% ($\kappa = 0.64-1.00$), and at movement 85.3% to 97.1% ($\kappa = 0.64-0.84$). A cutoff of ≥ 2 on the PAINAD was used to indicate the presence of pain.⁵⁸

For self-reported pain, participants were shown and read a piece of paper printed in large type with the question “Are you in pain?” They were asked to answer “yes” or “no” or indicate these responses by pointing at the paper. They were then shown the Wong-Baker FACES scale, line drawings of 7 faces indicating increasing amounts of pain.¹⁸

After pain assessment, agitation was assessed by a different research assistant. The Cohen–Mansfield Agitation Inventory (CMAI) is a scale describing 29 agitated behaviours, each of which is rated on a 7-point frequency scale, from 1 indicating not present to 7 indicating several times an hour.¹⁰ The range is from 29 to 203 with a cutoff score of 39 and above indicating clinically significant agitation.⁴

We also used the Behavioural Pathology in Alzheimer Disease Scale (BEHAVE-AD).⁴⁰ This rates 7 domains: paranoid and delusional ideation, hallucinations, activity disturbances, aggressiveness, diurnal rhythm disturbance, affective disturbance, and anxieties and phobias. Scores are generated for the presence or absence (0/1) and severity of symptoms (0 = none, 1 = mild, 2 = moderate, and 3 = severe) (maximum score = 75). To complete the CMAI and the BEHAVE-AD, we observed the participants and gathered information from a range of sources including discussions with families, ward staff, and hospital notes. Data were collected at study entry and then every 4 (± 1) days for pain and BPSD, until discharge, death, or “awaiting placement” in a care home.

2.3. Sample size

We could not find any previous studies of pain prevalence in people with dementia in acute medical wards. Using a predicted prevalence of pain of 55% from a care home sample of people with dementia,⁵⁰ we calculated that 250 participants would ensure a 95% confidence interval for pain prevalence with 6% precision. For our analyses exploring the association between pain and agitation, we took data from a study of pain in people with dementia that used the CMAI.⁴⁹ To analyse the hypothesised association between pain and BPSD, we use repeated measures (every 4 ± 1 days). Power depends on the correlation between measurements, which we are unable to predict. We can calculate a conservative estimate by considering a perfect correlation between repeated measurements ($\rho = 1$). Shega et al.⁴⁹ reported a mean CMAI score of 50.5 and 42.5 in patients with and without pain, respectively (standard deviation 18.9). Assuming the presence of pain in 55% of our sample,⁵⁰ the power to detect a significant difference with 250 patients would be 91%.

2.4. Data analysis

We calculated estimates of prevalence with 95% confidence intervals (CI) for pain (self-reported, or observed using PAINAD at rest and on movement) at study entry, at any time during the admission, and over all study assessments ($n = 965$). Generalised estimating equations (GEE) were used to compute prevalence and 95% confidence intervals over all assessments during the admission, to take into account repeated measurements within participants.

“Persistent pain” was defined as present in participants who were assessed 3 or more times (the median number of assessments per participant in this project) if pain was recorded on at least 75% of their study assessments. We created the variable “undetected pain” for those in whom we recorded any pain throughout admission, on movement or at rest, and no analgesics were prescribed. If they were prescribed analgesia, this was defined as “detected pain.”⁵⁰ We tested for associations between demographic and clinical characteristics of the participants and the presence of pain during admission using χ^2 or Fisher’s exact test, as appropriate.

We examined the association between PAINAD score and the total CMAI, and then BEHAVE-AD total scores using GEEs with exchangeable correlation structures and robust standard errors. For pain during movement, we first examined the crude association, and then adjusted for potential confounders of the association between pain and BPSD: age, gender, FAST score, comorbidity and acute illness (cause of admission), and hospital site. For comparison, we repeated the fully controlled analysis for pain at rest. Because delirium is associated with behavioural disturbance, we repeated this analysis excluding participants with delirium as a sensitivity analysis.

The association between pain and BPSD measures could occur because observational pain scales capture symptoms of distress²⁹ ie, there is possible overlap between some items included in both behavioural and pain scales. Because of the potential overlap in symptoms used by both scales, we conducted a sensitivity analysis, whereby a 4-member independent panel examined each item on the PAINAD and BEHAVE-AD for duplication. All agreed that 3 items were duplicated by the BEHAVE-AD (D16-verbal outbursts, D17-physical threats, and F20-tearfulness); 3 of 4 raters agreed that there was duplication on 2 items (C14-pacing and purposeless activity and F21-depressed mood). The GEE models were therefore repeated with all 5 duplicate items removed.

2.5. Ethical issues

Our consent procedure followed the England and Wales Mental Capacity Act (2005). If a participant agreed and had capacity, we obtained written informed consent. If they did not have capacity, we identified a personal consultee to give agreement. This could be given verbally over the telephone, and the consultee was posted an agreement form to sign and return. If forms were not returned, participants’ data were destroyed. If we could not contact a personal consultee within 48 hours of screening, a professional consultee (senior member of a clinical team not directly involved in research or patient care) gave agreement. See Ref. 46 for a detailed description.

3. Results

We screened 1612 potential participants (Fig. 1). The most common reasons for exclusion were MMSE score of >24 or AMTS score >7 or patients being discharged before they could be assessed. Of 292 assessed, 62 were excluded because they did not fulfil the inclusion criteria or because carers who gave telephone agreement did not return signed forms, giving 230 participants recruited to the study (117 from hospital 1 and 113 from hospital 2). The median length of admission was 12 days (range, 2-72; interquartile range [IQR] 7-23) with a median of 3 study assessments per participant (range, 1-20; IQR 2-5). No participants dropped out during the study. There were no significant differences between participants from hospital sites 1 and 2 with respect to gender, proportion with a previous dementia diagnosis, usual

residence, or Charlson score. Hospital 1 participants were significantly older ($t = -2.26$, $P = 0.025$) and more were of white British origin (82.0% at hospital 1 vs 69.0% at hospital 2, $\chi^2 = 25.9$, $P = 0.004$). Demographic and clinical features of the cohort and the frequency of BPSD are given in Table 1.

3.1. Prevalence and detection of pain

Only half of the participants (55.2%) could use the Wong-Baker FACES pain scale at baseline. Of those who could use the FACES scale, at baseline, 41% rated themselves as “very happy,” 9% as “hurts just a little bit,” 17% as “hurts a little more,” 17% as “hurts even more,” 8% as “hurts a whole lot,” and 7% as “hurts as much as you can imagine.”

Ability to use the FACES pain scale was significantly associated with dementia severity; 80.2% at FAST stage 3 to 5, 69.2% at FAST stage 6a-6c, 40.5% at FAST stage 6d-e, and only 3.2% of those at FAST stage 7 could use the scale (Fisher’s exact test = 65.2 $P < 0.001$). Therefore, we did not conduct further analyses using the FACES scale data.

At baseline assessment, 27.0% of participants self-reported that they were in pain. Using the PAINAD scale, 9.6% had pain at rest and 42.4% had pain on movement. Over the whole admission, 38.5% self-reported pain on at least 1 occasion; and on the PAINAD scale, 18.7% had pain during rest and 57.0% had observed pain during movement (Table 2). There were 138 participants with 3 or more assessments. These patients had a mean length of admission of 24.6 days (SD 15.6), a median admission of 19 days (IQR 13-32), and 15.6% of these had persistent pain on movement.

Few demographic or clinical factors were associated with self-reported pain, however, pain on movement and at rest was significantly associated with increasing age, having delirium on admission, and dying during hospital stay (Table 3).

3.2. Prescription of analgesic medication

Analgesics were prescribed for 174 (76%) participants during their admission. At the first study assessment (baseline), 70% of participants were prescribed regular or as-required paracetamol and 33% regular or as-required opiates (Table 4). During admission, 18% of participants had changes made to their analgesia; prescribing of as-required paracetamol and regular opiates increased. Among those who experienced pain during admission, 12% were not prescribed analgesics.

3.3. Prevalence of agitation and other psychiatric symptoms of dementia

The median score on the CMAI, at the first assessment was 31.0 (IQR 29-35). The median CMAI score for all study visits was 30.5 (IQR 29-35), and the mean 33.0 (SD 5.5) and 24.8% of participants scored above the cutoff score (39 and above) indicating they had clinically significant agitation⁴ on at least 1 occasion during their admission. Psychiatric symptoms of dementia were experienced by 75% of participants during their admission as measured on the BEHAVE-AD scale, the commonest symptoms being aggression, activity, and sleep disturbance (Table 1). See Ref. 43 for further information on the prevalence of BPSD in this population.

3.4. Association between pain, agitation, and other psychiatric symptoms of dementia

We found no significant association between pain and agitation, as measured by the CMAI. However, there was significant

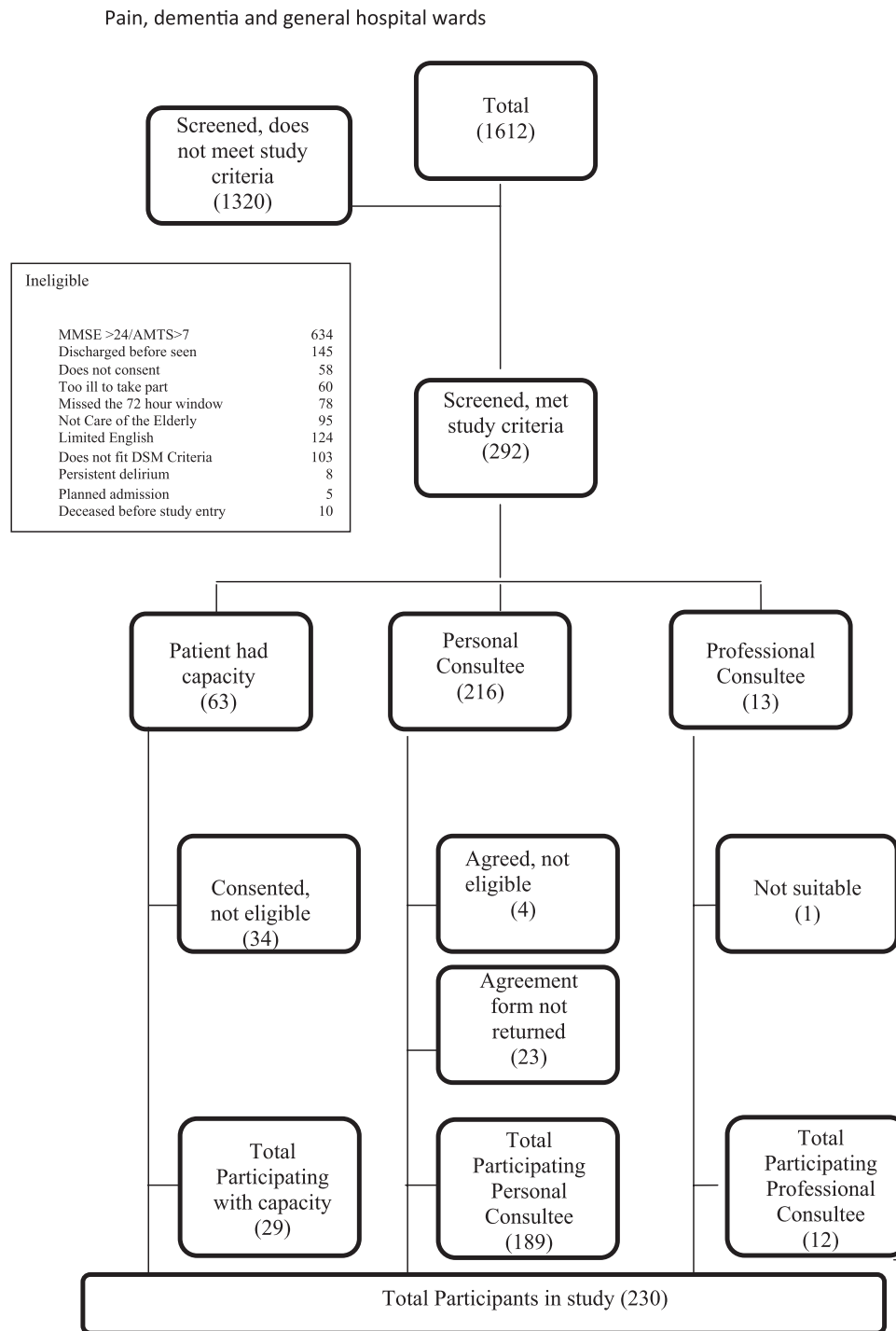


Figure 1. Study recruitment flowchart.

association between the total BEHAVE-AD score and pain at movement and at rest. This association remained significant after controlling for age, gender, hospital site, FAST score, Charlson score, and reason for admission, and also after excluding patients with delirium (Table 5). For particular BPSD, in controlled analyses, we found that aggression and phobia or anxiety were associated with pain at movement and at rest.

On excluding items that overlapped between the PAINAD and the BEHAVE-AD (see Methods), we found that the association

between Pain and the BEHAVE-AD Scale remained significant in uncontrolled analysis and in controlled analyses examining pain at rest (Table 5).

4. Discussion

More than one-third of people with dementia reported pain at some time during admission, similar to community-dwelling older people and nursing home residents with dementia

Table 1
Characteristics of 230 older people with dementia and unplanned acute medical admission.

Demographics	Total cohort (N = 230)	
	N	%
Gender		
Female	151	66
Male	79	34
Age, y		
75-84	85	37
85-94	118	51
95+	27	12
Ethnicity		
White British	175	76
Black Caribbean	15	7
Other	40	17
Place of residence (n = 219)		
Home	147	67
Residential home	26	12
Nursing home	41	19
Other	5	2
Reason for admission (n = 229)		
Infections: lungs/skin/viral	79	34
Infections: UTI/blocked catheter	36	16
Fall/fracture/pain	31	14
Cardiac	22	10
Other	61	26
FAST score		
3-5 (objective functional deficit, difficulties with activities of daily living)	86	37
6a-6c (help required putting on clothes, toileting, or bathing)	39	17
6d-6e (urinary and faecal incontinence)	74	32
7a-f (<6 words, can no longer walk, sit up, smile, hold up head)	31	14
Charlson comorbidity score on admission		
0-1	57	25
2-3	124	54
4+	49	21
Waterlow score on admission (n = 174)		
0-9	18	10
10+	156	90
Delirium on admission (CAM) (n = 227)	26	11
CMAI score during whole admission (median, IQR)		31 (29, 35)
BPSD at any point during whole admission (BEHAVE-AD scale)		
Any symptom	172	75
Paranoia/delusions	26	11
Hallucination	34	15
Activity disturbance	101	44
Aggressive	130	56
Sleep disturbance	97	42
Affect	77	34
Phobia/anxiety	81	35
Length of admission (median, IQR), days		12 (7, 23)
Died during hospital admission	30	13

BEHAVE-AD, Behavioural Pathology in Alzheimer Disease Scale; BPSD, behavioural and psychiatric symptoms of dementia; CAM, Confusion Assessment Method; CMAI, Cohen–Mansfield Agitation Inventory; FAST, Functional Assessment Staging Scale; IQR, interquartile range; UTI, urinary tract infection.

(22%–33%).^{27,35,38,54} Pain prevalence rose when assessed by observation using the PAINAD; 57% had pain on movement at some time during their admission, and in 16%, this was persistent, occurring throughout their stay in hospital. This finding illustrates how self-report may lead to underestimation of pain in people with dementia and the importance of careful

observation for pain at rest and during movement. Many participants could not use the FACES pain scale, which is widely used in UK hospitals; this supports findings from care homes where only 36% of residents can correctly use self-assessment pain scales.⁸

Only older age was associated with increased prevalence of self-reported and observed pain (on movement and at rest). Those admitted with “falls, fracture, or pain” or “cardiac” events had lower pain prevalence. This may occur because clinicians perceive these to be potentially painful conditions and prescribe accordingly, but they may not consider “infections” to be painful conditions. The lack of clear proxy markers or associations with pain highlights the need for individual detailed pain assessment in the general hospital.⁴⁹

The association between pain and BPSD has previously been demonstrated in care homes^{1,54} but not in general hospitals. There was no association with agitated behaviours in general (as measured by the CMAI), but we did find a consistent association between total BEHAVE-AD scores, and the BEHAVE-AD subscale scores of aggression and anxiety with pain, both at movement and at rest.

The literature on whether pain is associated with agitation in people with dementia is inconsistent. Volicer et al.⁵⁵ found in a longitudinal study of 2032 Dutch nursing home residents that pain was not highly related to agitation and pain scores did not change in proportion to agitation scores. Other studies have found an association between agitation (measured on the CMAI) and pain in community-dwelling people with dementia; for every 1-point increase on the CMAI, there was a 3% increase in the likelihood of caregivers reporting pain (OR 1.03, 95% CI = 1.00–1.06, *P* = 0.049).⁴⁹

There are a number of reasons why these findings are inconsistent. The mean CMAI score in our population was lower than that found in other studies in community settings⁴⁹ or in care homes.²⁴ This may have occurred because our study participants were unwell, likely to be restricted to bed or chair and thus less able to express many of the behaviours listed in the CMAI, for example “pacing” or “trying to get to a different place.” In addition, “agitation” is a nonspecific and overarching term, and agitation scales such as the CMAI contain a wide range of items. It may be that specific types of agitation, such as “constant requests for attention” or “making strange noises,” are more strongly associated with pain.^{12,13}

Our finding of a strong association between pain and aggression, on the BEHAVE-AD, is more consistent with previous work.^{1,32} In support of this finding is the fact that pain severity has been found to be associated with the increasing frequency of aggressive behaviour.¹ It could be argued that when aggression occurs during movement, this is not just a reaction to pain but also fear or distress at the movement intervention itself. However, we found a strong association between observations of aggressive behaviour, which, on the BEHAVE-AD scale, includes “verbal outbursts” or “physical threats or other threatening behaviour” including “unaccustomed use of foul or abusive language” and pain at rest suggesting that this association is not just caused by resistance to, or rejection of care.

We also found a strong association between anxiety, as measured on the BEHAVE-AD and pain, in controlled analyses and at movement and at rest, and between pain and affective symptoms at rest. This concurs with the findings from other studies.²³ However, when pain is treated in people with dementia, although depression scores improve, anxiety does not.²³ The way the BEHAVE-AD scale measures anxiety may

Table 2**Prevalence of pain in 230 older people with dementia and unplanned acute medical admission.**

Pain	Time during admission, number (%)			
	At baseline, n = 230	At least once during admission, n = 230	All assessments n = 965*	Persistent, n = 138†
Self-reported	54/200 (27.0)	84/218 (38.5)	196/821 (23.9)	8/117 (6.8)
95% CI	(20.8, 33.2)	(32.0, 45.0)	(18.6, 27.5)	(2.2, 11.5)
PAINAD scale ≥ 2				
Pain during rest	22/229 (9.6)	43/230 (18.7)	68/950 (7.2)	0/135 (0.0)
95% CI	(5.8, 13.5)	(13.6, 23.8)	(5.3, 9.8)	-
Pain during movement	97/229 (42.4)	131/230 (57.0)	331/946 (35.0)	21/135 (15.6)
95% CI	(35.9, 48.8)	(50.5, 63.4)	(29.4, 39.0)	(9.4, 21.7)

* Prevalence for all assessments combined, estimated by generalised estimating equations.

† Defined in the population with 3 or more assessments, as in pain in at least 75% of the occasions.

CI, confidence interval; PAINAD, Pain Assessment in Advanced Dementia scale.

have influenced this finding. The anxiety subscale uses non-specific items that may indicate verbal agitation rather than diagnose an anxiety syndrome. In studies that use specific and validated anxiety tools, correlations between anxiety and pain are less strong.⁴⁵

We found no significant association between pain and “activity disturbance”; other studies have also found that the association between pain and BPSD is stronger for behaviours, which do not require ambulation and that pain is negatively associated with behaviours such as wandering.^{1,54}

Table 3**Associations between demographic and clinical characteristics and pain in 230 older people with unplanned acute medical admission.**

	Self-reported pain* (%)			Pain at rest* (%)			Pain on movement* (%)		
	Absent (n = 134)	Present (n = 84)	P	Absent (n = 187)	Present (n = 43)	P	Absent (n = 99)	Present (n = 131)	P
Gender			0.834			0.596			0.093
Female	62	38		80	20		39	61	
Male	60	40		84	16		51	49	
Age, y			0.280			0.034			0.035
75-84	59	41		86	14		41	59	
85-94	66	34		82	18		49	51	
95+	50	50		63	37		22	78	
Place of residence			0.526			0.178			0.474
Home	64	36		84	16		46	54	
Residential home	48	52		69	31		31	69	
Nursing home	61	39		83	17		39	61	
Other	67	33		60	40		40	60	
Reason for admission (n = 229)			0.028			0.120			0.169
Infections: lungs/skin/viral	50	50		78	22		37	63	
Infections: UTI/blocked catheter	53	47		69	31		33	67	
Fall/fracture/pain	71	29		87	13		42	58	
Cardiac	82	18		95	5		59	41	
Other	67	33		84	16		51	49	
FAST score			0.291			0.457			0.185
3-5 (functional deficit, difficulties with activities of daily living)	62	38		86	14		48	52	
6a-6c (help required putting on clothes, toileting, or bathing)	49	51		82	18		41	59	
6d-6e (urinary and faecal incontinence)	67	33		77	23		46	54	
7a-f (<6 words, can no longer walk, sit up, smile, hold up head)	67	33		77	23		26	74	
Charlson comorbidity score			0.222			0.556			0.209
0-1	52	48		77	23		37	63	
2-3	64	36		82	18		48	52	
4+	68	32		86	14		37	63	
Waterlow score			0.587			0.744			0.142
0-9	56	44		89	11		61	39	
10+	62	38		81	19		43	57	
Delirium on admission (CAM)			0.247			0.003			0.010
Yes	50	50		58	42		19	81	
No	63	37		84	16		46	54	
Died during hospital admission	56	44	0.550	60	40	0.004	17	83	0.002

* As found at least once during admission, P values calculated from χ^2 or Fisher's exact test.

CAM, Confusion Assessment Method; FAST, Functional Assessment Staging Scale; UTI, urinary tract infection.

Table 4
Prescription of analgesia to people with dementia during acute hospital admission.

	At baseline (n = 230)		During admission* (n = 185†)	
	n	%	n	%
Paracetamol				
None	68	30	48	26
Regular	103	45	61	33
As required	59	25	76	41
Nonsteroidal anti-inflammatory drugs				
None	229	99	184	99
Regular	1	1	0	0
As required	0	0	1	1
Opiates				
None	155	67	127	69
Regular	32	14	32	17
As required	43	19	26	14

* Data from any assessments after baseline.

† Forty-three participants had only 1 assessment (at baseline) and 2 had missing data on analgesic prescribing at follow-up.

4.1. Strengths and limitations

It is likely that our cohort was representative and our results can be generalised.⁴³ The prevalence of dementia and of BPSD are similar to those reported in other studies in this setting.^{17,42} Diagnosing dementia in the general hospital is challenging, but is important as many have not received a previous diagnosis. To reduce the risk of misclassification, we only diagnosed new cases of dementia in the absence of delirium, screening with the “maximum sensitivity” version of the CAM.

The acute hospital is a complex research environment, patients frequently move through wards and staff rotate. We attempted to overcome reporting bias by gathering information from numerous sources: family carers, our own observations, and medical and nursing notes. Recall bias may have led to over-reporting of “troublesome” behaviours. Our study has the strength of being based on primary data collection using repeated observations throughout the whole hospital admission, by trained research

staff. We controlled for a range of potential confounders, including delirium, but residual confounding may have occurred, in particular, mood can influence the association between pain and anxiety.⁴⁵ We conducted multiple analyses, and some significant findings may be due to chance.

Observational pain tools have been criticised.²⁹ The PAINAD has a high false-positive rate in care homes and is highly sensitive but may have low specificity.²⁸ Thus, our findings may overestimate the prevalence of pain. Observational pain tools may detect distress or other unmet needs caused by constipation or urinary symptoms or low mood or boredom.²⁹ However, it has been validated in the general hospital, has high concurrent validity against self-reported pain,¹⁵ has discriminant validity,¹⁵ and has construct validity⁶; and we found good interrater reliability.⁴³ In addition, we observed for pain at movement and at rest. The association between the total BEHAVE-AD score and pain persisted after sensitivity analysis where we removed items from the PAINAD that overlapped with those in the BEHAVE-AD scale.

4.2. Clinical implications

There is increasing public concern about the quality of care received by people with dementia in hospitals; they may be perceived as “resistive” and “difficult to manage” and prescribed inappropriate neuroleptic drugs. Some BPSD in the acute hospital may be due to underdetected and undermanaged pain. This then leads to a cycle whereby behavioural problems and rejection of care by the person with dementia can lead to dysfunctional coping in staff,¹⁴ increasing care burden and further alienating staff from the person with dementia.

The fact that pain may lead to behavioural disturbance is not controversial,¹ however, it is important to be precise and consider which specific behaviours are related to pain. This is vital in the stressful environment of the general hospital where staff may not have previous knowledge of the person with dementia. There may be a different behavioural “phenotype” of pain in this setting. Pain is particularly associated with aggression, even at rest.

Studies have highlighted lack of attention to depression in older people in hospital.¹⁷ Our results suggest that mood may be a useful indicator of pain in this setting. Antidepressants are not particularly effective in dementia⁵; however, a secondary analysis

Table 5
Associations between pain and behavioural and psychiatric symptoms of dementia, using generalised estimating equations in 230 older people with dementia and unplanned acute medical admission.

	PAINAD (pain during movement)									PAINAD (pain at rest)		
	Unadjusted (930 observations on 230 participants)			Adjusted* (928 observations on 229 participants)			Excluding those with delirium at baseline* (800 observations on 200 participants)			Adjusted* (932 observations on 229 participants)		
	Coef.	95% CI	P	Coef.	95% CI	P	Coef.	95% CI	P	Coef.	95% CI	P
CMAI	0.01	-0.00 to 0.03	0.160	0.01	-0.00 to 0.03	0.157	0.01	-0.01 to 0.02	0.524	0.01	-0.01 to 0.04	0.322
Total BEHAVE-AD score	0.21	0.08 to 0.35	0.002	0.20	0.07 to 0.32	0.002	0.17	0.03 to 0.31	0.008	0.41	0.14 to 0.69	0.003
Paranoia/delusions	0.00	-0.02 to 0.02	0.970	0.00	-0.01 to 0.02	0.997	0.00	-0.02 to 0.01	0.605	0.05	-0.02 to 0.11	0.181
Hallucination	-0.01	-0.03 to 0.01	0.209	-0.02	-0.03 to 0.00	0.115	-0.01	-0.03 to 0.01	0.082	-0.01	-0.06 to 0.04	0.747
Activity disturbance	-0.02	-0.05 to 0.01	0.243	-0.02	-0.05 to 0.01	0.292	-0.02	-0.05 to 0.02	0.185	-0.01	-0.08 to 0.06	0.815
Aggressive	0.17	0.09 to 0.24	<0.001	0.16	0.09 to 0.23	<0.001	0.13	0.05 to 0.20	<0.001	0.16	0.02 to 0.30	0.023
Sleep disturbance	0.01	-0.01 to 0.04	0.312	0.01	-0.02 to 0.03	0.462	0.01	-0.02 to 0.04	0.611	0.02	-0.04 to 0.09	0.475
Affect	0.01	-0.02 to 0.03	0.716	0.00	-0.02 to 0.03	0.799	0.01	-0.03 to 0.04	0.794	0.08	0.00 to 0.15	0.047
Phobia/anxiety	0.03	0.00 to 0.07	0.036	0.04	0.01 to 0.07	0.021	0.04	0.01 to 0.08	0.024	0.11	0.04 to 0.17	0.001
BEHAVE-AD scale removing PAINAD-related items	0.08	0.00 to 0.16	0.043	0.07	-0.01 to 0.14	0.069	0.06	-0.03 to 0.14	0.177	0.26	0.08 to 0.44	0.005

Results from generalised estimating equations, the coefficients (coef.) represent estimates of the mean difference in CMAI and BPSD score for each 1-point increase on the PAINAD score.

* Adjusted for age, gender, hospital, Functional Assessment Staging category, Charlson score, and the reason for admission.

Bold text indicates significance at <0.05 level.

BEHAVE-AD, Behavioural Pathology in Alzheimer Disease Scale; CI, confidence interval; CMAI, Cohen–Mansfield Agitating Inventory; PAINAD, Pain Assessment in Advanced Dementia scale.

from a randomised controlled trial of pain treatment for BPSD showed that depressive symptoms significantly improved.²³ Thus, improved detection of low mood in general hospitals could lead to improved pain management.

Enhancing pain assessment does not necessarily improve pain management.⁵⁹ We found that although 75% of participants were prescribed analgesics (mainly paracetamol), persistent pain was common, suggesting that as-required medication may not have been given or that pain symptoms may have been difficult to manage. Nonsteroidal anti-inflammatory drugs (NSAIDs) and opiates can have severe side effects in older people; NSAIDs have significant cardiac, gastrointestinal, and renal risks, whereas opiates can cause delirium and constipation. The clinical challenge is to balance these risks with those of undertreated pain and the distress that this can cause. There have been studies to optimise pain management and decrease BPSD in nursing homes,³⁰ and 1 trial has shown that behavioural problems, particularly verbal aggression, are improved by systematic pain management.²⁴ There have been no studies of such interventions in the general hospital. However, a number of barriers to improving pain management in hospitals have been identified, including poor knowledge of how to manage pain and irregular administration of as-required medications.⁵³ Improved pain management in hospitals would require complex interventions that both increase knowledge and facilitate the use of active implementation strategies.⁵³

Conflict of interest statement

The authors have no conflicts of interest to declare.

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[1] Ahn H, Horgas A. The relationship between pain and disruptive behaviors in nursing home resident with dementia. *BMC Geriatr* 2013;13:14.

- [2] Alzheimer's Society. Counting the cost: Caring for people with dementia on hospital wards. In: Lakkey L, editor. London: Alzheimer's Society, 2009.
- [3] American Psychiatric Association. Diagnostic and statistical manual of mental disorders. Washington DC: American Psychiatric Association, 1994.
- [4] Ballard C, Margallo-Lana M, Juszcak E, Douglas S, Swann A, Thomas A, O'Brien J, Everatt A, Sadler S, Maddison C, Lee L, Bannister C, Elvish R, Jacoby R. Quetiapine and rivastigmine and cognitive decline in Alzheimer's disease: randomised double blind placebo controlled trial. *BMJ* 2005;330:874.
- [5] Banerjee S, Hellier J, Dewey M, Romeo R, Ballard C, Baldwin R, Benthon P, Fox C, Holmes C, Katona C, Knapp M, Lawton C, Lindesay J, Livingston G, McCrae N, Moniz-Cook E, Murray J, Nurock S, Orrell M, O'Brien J, Poppe M, Thomas A, Walwyn R, Wilson K, Burns A. Sertraline or mirtazapine for depression in dementia (HTA-SADD): a randomised, multicentre, double-blind, placebo-controlled trial. *Lancet* 2011;378:403–11.
- [6] Basler HD, Huger D, Kunz R, Luckmann J, Lukas A, Nikolaus T, Schuler MS. Assessment of pain in advanced dementia. Construct validity of the German PAINAD [in German]. *Schmerz* 2006;20:519–26.
- [7] Charlson ME. Studies of prognosis: progress and pitfalls. *J Gen Intern Med* 1987;2:359–61.
- [8] Closs SJ, Barr B, Briggs M, Cash K, Seers K. A comparison of five pain assessment scales for nursing home residents with varying degrees of cognitive impairment. *J Pain Symptom Manage* 2004;27:196–205.
- [9] Coen RF, Swanwick GR, O'Boyle CA, Coakley D. Behaviour disturbance and other predictors of carer burden in Alzheimer's disease. *Int J Geriatr Psychiatry* 1997;12:331–6.
- [10] Cohen-Mansfield J, Libin A. Assessment of agitation in elderly patients with dementia: correlations between informant rating and direct observation. *Int J Geriatr Psychiatry* 2004;19:881–91.
- [11] Cohen-Mansfield J, Marx MS, Rosenthal AS. A description of agitation in a nursing home. *J Gerontol* 1989;44:M77–84.
- [12] Cohen-Mansfield J, Marx MS, Werner P. Agitation in elderly persons: an integrative report of findings in a nursing home. *Int Psychogeriatr* 1992;4 (suppl 2):221–40.
- [13] Cohen-Mansfield J, Werner P. Longitudinal predictors of non-aggressive agitated behaviors in the elderly. *Int J Geriatr Psychiatry* 1999;14:831–44.
- [14] Cooper C, Dow B, Hay S, Livingston D, Livingston G. Care workers' abusive behavior to residents in care homes: a qualitative study of types of abuse, barriers, and facilitators to good care and development of an instrument for reporting of abuse anonymously. *Int Psychogeriatr* 2013; 25:733–41.
- [15] DeWaters T, Faut-Callahan M, McCann JJ, Paice JA, Fogg L, Hollinger-Smith L, Sikorski K, Stanaitis H. Comparison of self-reported pain and the PAINAD scale in hospitalized cognitively impaired and intact older adults after hip fracture surgery. *Orthop Nurs* 2008;27:21–8.
- [16] Folstein MF, Folstein SE, McHugh PR. "Mini-mental state." A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975;12:189–98.
- [17] Goldberg SE, Whittamore KH, Harwood RH, Bradshaw LE, Gladman JR, Jones RG. The prevalence of mental health problems among older adults admitted as an emergency to a general hospital. *Age Ageing* 2012;41: 80–6.
- [18] Herr KA, Mobily PR, Kohout FJ, Wagenaar D. Evaluation of the Faces Pain Scale for use with the elderly. *Clin J Pain* 1998;14:29–38.
- [19] Hodkinson HM. Evaluation of a mental test score for assessment of mental impairment in the elderly. *Age Ageing* 1972;1:233–8.
- [20] Horgas AL, Tsai PF. Analgesic drug prescription and use in cognitively impaired nursing home residents. *Nurs Res* 1998;47:235–42.
- [21] Hurt C, Bhattacharyya S, Burns A, Camus V, Liperoti R, Marriott A, Nobili F, Robert P, Tsolaki M, Vellas B, Verhey F, Byrne EJ. Patient and caregiver perspectives of quality of life in dementia. An investigation of the relationship to behavioural and psychological symptoms in dementia. *Dement Geriatr Cogn Disord* 2008;26:138–46.
- [22] Husebo BS, Ballard C, Aarsland D. Pain treatment of agitation in patients with dementia: a systematic review. *Int J Geriatr Psychiatry* 2011;26: 1012–18.
- [23] Husebo BS, Ballard C, Fritze F, Sandvik RK, Aarsland D. Efficacy of pain treatment on mood syndrome in patients with dementia: a randomized clinical trial. *Int J Geriatr Psychiatry* 2014;29:828–36.
- [24] Husebo BS, Ballard C, Sandvik R, Nilsen OB, Aarsland D. Efficacy of treating pain to reduce behavioural disturbances in residents of nursing homes with dementia: cluster randomised clinical trial. *BMJ* 2011;343: d4065.
- [25] Inouye SK, van Dyck CH, Alessi CA, Balkin S, Siegel AP, Horwitz RI. Clarifying confusion: the confusion assessment method. A new method for detection of delirium. *Ann Intern Med* 1990;113:941–8.

- [26] Ishii S, Streim JE, Saliba D. A conceptual framework for rejection of care behaviors: review of literature and analysis of role of dementia severity. *J Am Med Dir Assoc* 2012;13:11–23.
- [27] Jensen-Dahm C, Vogel A, Waldorff FB, Waldemar G. Discrepancy between self-and proxy-rated pain in Alzheimer's disease: results from the Danish Alzheimer Intervention Study. *J Am Geriatr Soc* 2012;60:1274–8.
- [28] Jordan A, Hughes J, Pakresi M, Hepburn S, O'Brien JT. The utility of PAINAD in assessing pain in a UK population with severe dementia. *Int J Geriatr Psychiatry* 2011;26:118–26.
- [29] Jordan A, Regnard C, O'Brien JT, Hughes JC. Pain and distress in advanced dementia: choosing the right tools for the job. *Palliat Med* 2012;26:873–8.
- [30] Kovach CR, Noonan PE, Schliedt AM, Reynolds S, Wells T. The serial trial intervention: an innovative approach to meeting needs of individuals with dementia. *J Gerontol Nurs* 2006;32:18–25.
- [31] Kovach CR, Noonan PE, Schliedt AM, Wells T. A model of consequences of need-driven, dementia-compromised behavior. *J Nurs Scholarsh* 2005;37:134–40.
- [32] Kunik ME, Snow AL, Davila JA, Steele AB, Balasubramanyam V, Doody RS, Schulz PE, Kalavar JS, Morgan RO. Causes of aggressive behavior in patients with dementia. *J Clin Psychiatry* 2010;71:1145–52.
- [33] Laurila JV, Pitkala KH, Strandberg TE, Tilvis RS. Detection and documentation of dementia and delirium in acute geriatric wards. *Gen Hosp Psychiatry* 2004;26:31–5.
- [34] Lautenbacher S. Pain assessment in special patient groups such as those with dementia: At the finishing line or just starting from scratch? *PAIN* 2014;155:1419–20.
- [35] Mantyselka P, Hartikainen S, Louhivuori-Laako K, Sulkava R. Effects of dementia on perceived daily pain in home-dwelling elderly people: a population-based study. *Age Ageing* 2004;33:496–9.
- [36] Murman DL, Colenda CC. The economic impact of neuropsychiatric symptoms in Alzheimer's disease: can drugs ease the burden? *Pharmacoeconomics* 2005;23:227–42.
- [37] Oosterman JM, de VK, Dijkerman HC, de Haan EH, Scherder EJ. Exploring the relationship between cognition and self-reported pain in residents of homes for the elderly. *Int Psychogeriatr* 2009;21:157–63.
- [38] Pautex S, Herrmann F, Le LP, Fabjan M, Michel JP, Gold G. Feasibility and reliability of four pain self-assessment scales and correlation with an observational rating scale in hospitalized elderly demented patients. *J Gerontol A Biol Sci Med Sci* 2005;60:524–9.
- [39] Reisberg B. Functional assessment staging (FAST). *Psychopharmacol Bull* 1988;24:653–9.
- [40] Reisberg B, Borenstein J, Salob SP, Ferris SH, Franssen E, Georgotas A. Behavioral symptoms in Alzheimer's disease: phenomenology and treatment. *J Clin Psychiatry* 1987;48(suppl):9–15.
- [41] Ryden MB, Feldt KS, Oh HL, Brand K, Warne M, Weber E, Nelson J, Gross C. Relationships between aggressive behavior in cognitively impaired nursing home residents and use of restraints, psychoactive drugs, and secured units. *Arch Psychiatr Nurs* 1999;13:170–8.
- [42] Sampson EL, Blanchard MR, Jones L, Tookman A, King M. Dementia in the acute hospital: prospective cohort study of prevalence and mortality. *Br J Psychiatry* 2009;195:61–6.
- [43] Sampson EL, White N, Leurent B, Scott S, Lord K, Round J, Jones L. Behavioural and psychiatric symptoms in people with dementia admitted to the acute hospital: prospective cohort study. *Br J Psychiatry* 2014;205:189–96.
- [44] Scherder E, Herr K, Pickering G, Gibson S, Benedetti F, Lautenbacher S. Pain in dementia. *PAIN* 2009;145:276–8.
- [45] Scherder EJ, Eggermont L, Plooi B, Oudshoorn J, Vuijk PJ, Pickering G, Lautenbacher S, Achterberg W, Oosterman J. Relationship between chronic pain and cognition in cognitively intact older persons and in patients with Alzheimer's disease. The need to control for mood. *Gerontology* 2008;54:50–8.
- [46] Scott S, Jones L, Blanchard MR, Sampson EL. Study Protocol: the Behaviour and Pain in Dementia Study (BePAID). *BMC Geriatr* 2011; 11:61.
- [47] Sengstaken EA, King SA. The problems of pain and its detection among geriatric nursing home residents. *J Am Geriatr Soc* 1993;41:541–4.
- [48] Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA. Pain in community-dwelling persons with dementia: frequency, intensity, and congruence between patient and caregiver report. *J Pain Symptom Manage* 2004;28:585–92.
- [49] Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA. Factors associated with self- and caregiver report of pain among community-dwelling persons with dementia. *J Palliat Med* 2005;8: 567–75.
- [50] Shega JW, Hougham GW, Stocking CB, Cox-Hayley D, Sachs GA. Management of noncancer pain in community-dwelling persons with dementia. *J Am Geriatr Soc* 2006;54:1892–7.
- [51] Steinberg M, Shao H, Zandi P, Lyketsos CG, Welsh-Bohmer KA, Norton MC, Breitner JC, Steffens DC, Tschanz JT. Point and 5-year period prevalence of neuropsychiatric symptoms in dementia: the Cache County Study. *Int J Geriatr Psychiatry* 2008;23:170–7.
- [52] Takai Y, Yamamoto-Mitani N, Okamoto Y, Koyama K, Honda A. Literature review of pain prevalence among older residents of nursing homes. *Pain Manag Nurs* 2010;11:209–23.
- [53] Titler MG, Herr K, Schilling ML, Marsh JL, Xie XJ, Ardery G, Clarke WR, Everett LQ. Acute pain treatment for older adults hospitalized with hip fracture: current nursing practices and perceived barriers. *Appl Nurs Res* 2003;16:211–27.
- [54] Tosato M, Lukas A, van der Roest HG, Danese P, Antocicco M, Finne-Soveri H, Nikolaus T, Landi F, Bernabei R, Onder G. Association of pain with behavioral and psychiatric symptoms among nursing home residents with cognitive impairment: results from the SHELTER study. *PAIN* 2012;153:305–10.
- [55] Volicer L, Frijters DH, van der Steen JT. Relationship between symptoms of depression and agitation in nursing home residents with dementia. *Int J Geriatr Psychiatry* 2012;27:749–54.
- [56] Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc* 2003;4:9–15.
- [57] Waterlow J. Pressure sores: a risk assessment card. *Nurs Times* 1985; 81:49–55.
- [58] Zwakhalen SM, van der Steen JT, Najim MD. Which score most likely represents pain on the observational PAINAD pain scale for patients with dementia? *J Am Med Dir Assoc* 2012;13:384–9.
- [59] Zwakhalen SM, van't Hof CE, Hamers JP. Systematic pain assessment using an observational scale in nursing home residents with dementia: exploring feasibility and applied interventions. *J Clin Nurs* 2012;21: 3009–17.