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Pain reports and pain medication treatment in nursing home residents with and without dementia

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Abstract

Aim—The purpose of this pilot study was to determine if a diagnosis of dementia influenced pain self-reports and pain medication use in a group of verbally communicative nursing home (NH) residents.

Methods—The study design was a between groups, cross-sectional chart audit and a seven-question structured pain interview comparing outcomes in residents with and without a diagnosis of dementia. The study was carried out at a large metropolitan NH in the southern USA. The participants consisted of 52 long-stay NH residents capable of self-consent with at least one order for pain medication (opioid or non-narcotic) either *pro re nata*, scheduled or both. Approximately 40% ($n = 20$) had a diagnosis of dementia.

Results—Although each group had similar pain-related diagnoses, residents without a dementia diagnosis were significantly more likely to have a medication order for an opioid (OR 4.37, 95% CI 1.29–14.73, $P = 0.018$). Based on self-reported pain interview responses, no statistically significant differences were identified between the groups for chronic pain symptoms. However, among residents who reported current pain, those with a dementia diagnosis reported greater pain intensity (based on a 0–10 numeric rating scale) than did those without dementia (median 8.0 vs 6.0, respectively; $P = 0.010$).

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Disclosure statement

The authors have no conflicts of interest to report.

Conclusions—Verbally communicative NH residents with mild and moderate cognitive impairment can report their pain symptoms and pain intensity. Nurses in long-term care might assume that residents with dementia cannot reliably self-report their pain; however, suffering from untreated severe pain could exacerbate cognitive impairment, worsen functional impairment and severely impair sleep. A brief, focused pain interview might be one method for increasing the detection of moderate to severe pain in verbally communicative NH residents with dementia.

Keywords

clinical medicine; dementia; nursing; pain; pain assessment; quality of life; sociomedical science

Introduction

Pain is the primary reason that people seek medical attention,¹ and a majority of people seeking pain treatment are aged over 60 years.² Estimates are that nearly 40% of all older adults report pain that interferes with activities of daily living.³ The consequences of untreated pain include impaired quality of life, sleep disturbances, weakened immune system, increased cognitive impairment and functional loss,^{4–6} and appropriate pain management leads to better outcomes.⁷ The prevalence of dementia⁸ and pain⁹ both increase with advancing age, and the prevalence of pain among nursing home (NH) residents is estimated to be between 45% and 83%.^{10–14} Thus, many NH residents with dementia also have pain.

Human autopsy¹⁵ and functional neuroimaging studies^{16,17} have shown that dementia pathology affects both the sensory (lateral) and affective (medial) pain systems.¹⁸ Regions of the medial pain system are affected earlier in the course of dementia, whereas regions of the lateral system are generally spared until late dementia.¹⁵ Damage to the lateral and medial pain networks supports the hypothesis that people with dementia might have altered sensory and affective verbal reports of pain that could require different assessment strategies.^{19,20}

Current research evidence regarding pain in people with dementia has shown mixed findings. Reasons for mixed findings include differences in the pain stimulus used (e.g. mechanical pressure, thermal, or electrical shock) or the type of pain examined in observational studies (acute *vs* chronic). Some studies show diminished sensory, affective and behavioral responses to pain, whereas other studies suggest a normal or increased response to pain in dementia.^{16,21–28} Cognitively impaired people generally receive less opioid medication, even when they have medical conditions known to be moderately to severely painful in people who are cognitively intact.^{29–32} Patient preference might not strongly impact treatment outcomes. One study found that NH residents with chronic pain who reported a preference for *pro re nata* (PRN) pain medication did not receive PRN pain medication more frequently than residents who reported a preference to not receive PRN pain medication.³³ In fact, both groups infrequently received PRN medications (less than once daily).³³

Despite evidence that many people with dementia can reliably report their pain,^{34,35} reasons for poor pain management in older adults with dementia remain unanswered.^{36–38,48} Understanding the reasons for, and identifying outcomes related to, poor pain management

in NH residents with mild to moderate dementia is critical to designing effective pain management strategies in this vulnerable population of older adults.³⁹ Identifying reasons for poor pain management earlier in the course of illness might help inform pain management in those with severe disease. The purpose of the present pilot study was to examine pain among a group of verbally communicative NH residents with and without mild or moderate dementia. Specifically, residents with intact reasoning skills were targeted. Intact reasoning skills were determined by assessing the individual's capacity to understand the research procedures and by providing self-consent to participate in the study. The following hypotheses were tested:

1. When compared with residents without a dementia diagnosis, residents with mild and moderate dementia will be prescribed less opioid medication, relative to non-narcotic, to treat their pain.
2. When compared with residents without a dementia diagnosis, residents with mild and moderate dementia will self-report more pain intensity, less sleep and greater functional impairment, in response to a structured interview.

Method

Participants and setting

Participants were recruited from one 240-bed, for-profit NH in the mid-southern region of the USA as part of a quality improvement (QI) project. Overall, the facility had a 92% occupancy rate at the time of the study, which included short-stay, long-stay and hospice beds. This pilot study included only the long-stay beds (221 total occupied beds). All study procedures were approved by the university-affiliated institutional review board. Total staffing (licensed nurses + nurse aides) hours per resident per day (hprd) reported to the United States Centers for Medicare and Medicaid Services at the time of the study was 4.07 hprd, which placed this facility in a high staffing level based on national averages. The Director-of-Nursing reported licensed nurse ((Registered Nurses [RN] + Licensed Practical Nurse [LPN]) ratios of 1:17 on the day shift and 1:27 on the evening shift.

Inclusion/exclusion criteria

To increase sample homogeneity, residents were initially eligible for study inclusion if they were in "longstay status" (no "short stay" or hospice care) and had an order for pain medication (scheduled or PRN; non-narcotic, or opioid). Because we were interested in determining how pain is reported and managed during the early stages of dementia, people with dementia who had the capacity to self-consent were included in this study. Self-consent was initially determined by chart documentation and then verified with a standardized evaluation wherein each participant was asked three structured questions to evaluate their understanding of study procedures after review of the consent form (i.e. "Can you name one thing that will happen if you participate in the study?", "What can you do to withdraw from the study?", "What types of questions will we ask you as part of this study?"). The resident was considered able to self-consent only if all three questions were correctly answered. Of 104 eligible residents identified in the initial chart review, 52 (50%) residents meeting inclusion criteria were able to self-consent to participate.

Study design

Between-groups cross-sectional medical chart audits and a seven-question brief pain interview were carried out by trained research assistants over the initial baseline period of a larger QI intervention study. The baseline period included two full weeks (14 days) of medical chart data across morning, evening and night shifts, and one pain interview per participant during this same 2-week time period.

Measures

Minimum dataset (2.0)—Nursing homes in several countries, use the minimum dataset (MDS) to assess residents on admission, quarterly and when there is a significant change in health status.⁴⁰ The MDS includes over 250 assessment items on demographic, diagnostic, clinical, functional, psychosocial and cognitive status.⁴¹ Nursing staff complete the MDS based on the previous week's activities, and input from families and coworkers.⁴² The MDS has strong interrater item reliability (>0.75),⁴³ and the MDS is reliable for data collection in NH residents on some measures.⁴⁴ Cognitive and functional ability assessment instruments have been derived from the MDS. These include the Cognitive Performance Scale (CPS)⁴¹ and the Activities of Daily Living Assessment Summary Scale (ADLS).⁴⁵ Cognitive and functional measures were calculated from the most recent MDS 2.0 assessment (quarterly or annual) for each participant at the time of the study.

Cognitive ability—The Cognitive Performance Scale⁴¹ was developed from five MDS 2.0 items relevant to cognitive ability (i.e. comatose, short- and long-term memory, communication, and cognitive skills for decision-making). The CPS is scored from 0 to 6, indicating no impairment (score = 0), borderline impairment (score = 1), mild impairment (score = 2), moderate impairment (score = 3), moderately severe impairment (score = 4), severe impairment (score = 5) and very severe impairment or comatose status (score = 6).⁴¹ Based on the capacity to self-consent during the screening interview (see Inclusion/Exclusion Criteria), individuals with scores from 0 to 4 were included in this pilot study. The CPS tool developers reported interrater reliability at 0.85,⁴¹ and the CPS has been reported to be both reliable and valid.⁴⁷

Functional ability—The Activities of Daily Living (ADL) Summary Scale was developed from seven MDS 2.0 items that are indicative of functional ability.⁴⁵ The MDS ADL scale has excellent reliability and strong internal consistency ($\alpha = 0.94$), with a possible score range from 0 to 28 and a mean score of 15.24 ($SD = 9.25$) in national averages.⁴⁵ Each item is scored from 0 to 4. A MDS-derived ADL total score of 0 indicates staff ratings of the resident being completely independent with all ADL, whereas a score of 28 shows total dependence in all ADL.⁴⁵

Chart abstractions—After recording demographic data (length of stay, age, sex, and ethnicity), medical record reviews were carried out by trained research staff using a standardized chart abstraction tool. Items in the chart abstraction review included the number of PRN and scheduled pain medications given during the 2-week baseline period. Also, the type of pain medicine (i.e. opioid, non-narcotic), and the frequency of pain administration documentation by licensed nurses were recorded.

Resident interview—Trained research staff carried out a structured pain interview with each participant during the same 2-week baseline period that pain medications were reviewed in participants' medical records. Specifically, resident interviews were carried out either during the day or evening shift within a 3-day period. The interview questions were part of a standardized resident interview³⁶ derived from a modified version of the Geriatric Pain Measure. A "yes" response to question 2 (do you have pain every day?), or three or more "yes" responses to questions 1–4 below indicate the presence of probable chronic pain. Previous studies have concluded that the Geriatric Pain Measure is a reliable and valid assessment of probable chronic pain in NH residents with and without dementia.^{33,35,36}

1. Do you have pain now? If yes, what is your pain level from 0–10?
2. Do you have pain every day?
3. Does pain keep you from sleeping at night?
4. Does pain keep you from participating in activities?
5. Do you tell the nurse about your pain?
6. Does the nursing staff ask about your pain?
7. Would you prefer to take pain medications for your pain?

Analysis

Participant characteristics (shown in Table 1) were compared between those with and without a dementia diagnosis. Frequency distributions were used to generate rates of opioid prescription based on medical record documentation and self-reported pain based on interview. As a result of highly skewed continuous or ordinal data distributions (e.g. pain intensity, ADL scores, CPS scores), median and 25–75th interquartile range (IQR) values were used to describe those distributions. The χ^2 -test of independence was used to compare the rate distributions in the group with a dementia diagnosis ($n = 20$) and the group without a dementia diagnosis ($n = 32$). The Mann–Whitney test was used for the respective comparison of the continuous and ordinal data. Odds ratio and 95% confidence interval for differences in the rates of opioid prescription between the groups was generated using logistic regression. An alpha of 0.05 ($P < 0.05$) was used for determining statistical significance.

Results

Participant characteristics

Participant characteristics of the sample are summarized in Table 1. The median age for the total sample ($n = 52$) was 84 years, and their median length of NH stay at the time of the study was 10.4 months. Most of the participants were female (65%) and white (71%). Across both groups, residents had a median of four pain-related diagnoses (min = 1, max = 7). Pain-related diagnoses included: fractures, chest pain, osteoarthritis, rheumatoid arthritis, shingles, migraines, back pain, cancer, cellulitis, degenerative joint disease, neuropathy, pancreatitis, gout and spinal stenosis (most common were osteoarthritis and degenerative joint disease). No statistically significant differences were found between the residents with

and without a diagnosis of dementia on any of the demographic or clinical characteristics shown in Table 1, with the exception of cognition. Residents with a dementia diagnosis had greater cognitive impairment (higher CPS scores) than did those residents without such a diagnosis (median = 3.0 *vs* median = 2.0; $P = 0.001$) and, although not statistically significant, tended to have lower functional independence (ADL median 16.0 *vs* 18.0; $P = 0.087$).

Pain orders and pain medication administration

Although there was not a statistically significant difference between the groups of residents in total number of pain diagnoses (see Table 1), residents without a dementia diagnosis were more likely to have an opioid or both an opioid and a non-narcotic prescription for their pain compared with those residents with a dementia diagnosis (Table 2. Opioid/Both: Without Dementia 78%, With Dementia 45%, OR 4.37, 95% CI 1.29– 14.73, $P = 0.018$). There were no statistically significant differences in the rates of administration of the prescribed medications between the two groups, however, during the 2-week period of data collection procedures (see Table 2).

Pain interview and assessment

Of the 52 study participants, seven had incomplete interview data due to: being away from their room, receiving rehabilitation services, or refusal to answer interview questions. Of the remaining 45 participants who completed the pain interview, 56% reported having pain at the time of the interview, whereas approximately 67% ($n = 30$ of 45) reported having pain every day (see Table 3). Importantly, there were no statistically significant differences between those with and without a dementia diagnosis in the prevalence of pain symptoms, likelihood of probable chronic pain and preference for taking pain medication. Despite these findings, among residents reporting having pain and who subsequently rated the intensity of their pain using a 0–10 intensity scale ($n = 22$), those with dementia reported higher levels of pain than did those without a dementia diagnosis (median 8.0 *vs* 6.0 respectively, $P = 0.010$; see Table 3). All of the residents with dementia (9/9, 100%) gave ratings in the moderate to severe range (>4), whereas 61.5% (8/13) residents without dementia gave intensity ratings in this same range. In addition, although the small study sample precluded statistical significance, some clinically important trends were found. Participants with a dementia diagnosis were less likely to report that they tell the nursing staff about their pain than participants without dementia (79% *vs* 96%, respectively, $P = 0.070$), less likely to report that the nursing staff asks about their pain (63% *vs* 85%, respectively, $P = 0.098$) and more likely to report pain interfering with sleep (68% *vs* 46%, respectively, $P = 0.138$; see Table 3).

Discussion

The purpose of the present pilot study was to examine pain reports and pain medication use in a group of verbally communicative NH residents with and without a diagnosis of mild to moderate dementia. On average, NH residents with dementia were moderately cognitively impaired, and were prescribed and administered fewer opioids and reported more severe pain, whereas, residents without a dementia diagnosis were mildly cognitively impaired, and

were prescribed and administered more opioids and reported less severe pain. There also was a trend for lower functional ability in those with a dementia diagnosis.

Although residents with mild and moderate dementia were verbally communicative and able to report their pain intensity when asked directly by research staff, interview self-reports suggest that their motivation to report pain to nursing staff might be reduced. Similarly, the resident interview findings suggest that nursing staff might not routinely ask residents with dementia about their pain. Consistent with the results of other studies, licensed nurses might erroneously assume that NH residents with dementia are not able to reliably report their pain and, thus, would not ask routinely or that verbally communicative NH residents with dementia, who exhibit intact reasoning skills, will reliably report their pain and, thus, not ask routinely. These pilot results also show that a focused pain interview might be required to elicit pain symptoms and intensity in this vulnerable population of long-stay NH residents.

Since the time of data collection, the MDS 3.0 has been implemented, and it includes specific questions from the Geriatric Pain Measure to be used in conjunction with NH staff observational assessments of pain. In addition, the MDS 3.0 instructs NH staff to attempt a pain assessment interview with all residents, excluding only those who are comatose. Thus, findings from the current study support the MDS 3.0 guidance for nurses to include NH residents with mild and moderate cognitive impairment in pain interviews rather than relying solely on staff observational assessments of pain. Future studies should compare the sensitivity of the MDS 3.0 pain assessment relative to MDS 2.0 and also determine if the results of this preliminary study are replicated in the context of MDS 3.0.

A critical point to emphasize is that every resident in the current study had at least one pain medication ordered (PRN or scheduled). Also, each person in the current study was verbally communicative with the capacity to self-consent for research. Despite these facts, of the sample that reported currently being in pain, 77% (17 of 22) reported being in moderate or severe pain. Reasons for this phenomenon could include fear of not being heard, fear of becoming overly dependent, fear of addiction, a desire to please staff and a belief that their pain is “part of old age” – also, staff might express a lack of time to assess pain because they are dealing with residents with more overt behavioral disturbance, incontinence or falls.^{12,46} Neurobiological mechanisms not measured in the present study also could have influenced these results, such as damage to the central nervous system pain networks resulting from dementia pathology. The current pilot findings further highlight a possible decreased motivation to report pain or ask for pain medication in people with a diagnosis of dementia who can otherwise communicate well.

There were several limitations of the present study. First, the present pilot study included a small sample in only one NH site, which limits the external validity of the study. Second, the data collection period represented a brief time frame, just 2 weeks of usual NH care. Third, the frequency of pain medication administration was based solely on recorded data in the medical record. Fourth, the MDS 2.0 was used in the current study. Since the time of data collection procedures, the MDS 3.0 has been implemented with significant modifications to the pain assessment section. Despite these limitations, the results of the present pilot study are consistent with previous studies, showing that pain is both underdetected and

undertreated in the NH population, and that residents with dementia could be at higher risk for undertreatment relative to those without dementia, even when they retain their ability to communicate their pain to staff.^{33,35,36,49–51}

These pilot study findings show that low use of opioids continues to be a critical problem in NH residents with dementia. Preliminary findings suggest that although people with mild and moderate dementia can report pain intensity, they might be less motivated to report their pain to nursing staff. Despite research showing that suffering from untreated pain can contribute to greater cognitive impairment and functional loss, nursing staff in long-term care might erroneously assume that older adults with a diagnosis of dementia characteristically have lower cognition and functional ability – without considering pain as a contributing factor. The consequences of underreported or undertreated moderate to severe pain could be disabling or even deadly. Understanding the neurobiology of motivation, apathy, and pain in older adults with dementia are critical steps in designing effective pain management strategies and informing best practice models.

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References

1. American Pain Foundation. The problem with pain. 2011 Available from URL: <http://www.painfoundation.org/get-involved/problem-with-pain.html>.
2. Arita H, Hayashida M, Hanaoka K. Pain control for elderly patients in Japan. *Geriatr Gerontol Int*. 2004; 4:S239–S241.
3. Stewart W, Ricci J, Chee E, Morganstein D, Lipton R. Lost productive time and cost due to common pain conditions in the us workforce. *JAMA*. 2003; 290:2443–2454. [PubMed: 14612481]
4. Thomas E, Peat G, Harris L, Wilkie R, Croft P. The prevalence of pain and pain interference in a general population of older adults: cross-sectional findings from the North Staffordshire Osteoarthritis Project. *Pain*. 2004; 110(1):261–368.
5. AGS. The management of persistent pain in older persons. *J Am Geriatr Soc*. 2002; 50(6 Suppl):S205–S224. [PubMed: 12067390]
6. Leveille SG, Fried L, Guralnik JM. Disabling symptoms. *J Gen Intern Med*. 2002; 17:766–773. [PubMed: 12390552]
7. Nuevo FR. Acute pain in the elderly: management options. *Geriatr Gerontol Int*. 2004; 4:S243–S244.
8. Bryant LL, Grigsby J, Swenson C, Scarbro S, Baxter J. Chronic pain increases the risk of decreasing physical performance in older adults: the san luis valley health and aging study. *J Gerontol A Biol Sci Med Sci*. 2007; 62:989–996. [PubMed: 17895437]
9. Alzheimer's Disease International. World Alzheimer's Report 2010. 2010 <http://www.alz.co.uk/research/statistics.html>.
10. Català E, Reig E, Artés M, Aliaga L, López JS, Segú JL. Prevalence of pain in the Spanish population telephone survey in 5000 homes. *Eur J Pain*. 2002; 6:133–140. [PubMed: 11900473]
11. Shapiro RS. Liability issues in the management of pain. *J Pain Symptom Manage*. 1994; 9:146–152. [PubMed: 7516955]
12. Ferrell BA, Ferrell BR, Rivera L. Pain in cognitively impaired nursing home patients. *J Pain Symptom Manage*. 1995; 10:591–598. [PubMed: 8594119]
13. Roy R, Thomas M. A survey of chronic pain in an elderly population. *Can Fam Physician*. 1986; 32:513–516. [PubMed: 21267146]

14. Weiner D. Pain in nursing home residents: an exploration of prevalence, staff perspectives, and practical aspects of measurement. *Clin J Pain*. 1999; 15:92. [PubMed: 10382922]
15. Rub U, Del Tredici K, Del Turco D, Braak H. The intralaminar nuclei assigned to the medial pain system and other components of this system are early and progressively affected by the Alzheimer's disease-related cytoskeletal pathology. *J Chem Neuroanat*. 2002; 23:279–290. [PubMed: 12048111]
16. Cole L, Farrell M, Duff E, Barber J, Egan G, Gibson S. Pain sensitivity and fMRI pain-related brain activity in Alzheimer's disease. *Brain*. 2006; 129(Part 11):2957–2965. [PubMed: 16951408]
17. Cole L, Gavrilescu M, Johnston L, Gibson S, Farrell M, Egan G. The impact of Alzheimer's disease on the functional connectivity between brain regions underlying pain perception. *Eur J Pain*. 2011; 15:568.e561–568.e511. [PubMed: 21257326]
18. Monroe T, Gore J, Chen L, Mion LC, Cowan RL. Pain in people with Alzheimer's disease: potential applications for psychophysical and neurophysiological research. *J Geriatr Psychiatry Neurol*. 2012; 25:240–248. [PubMed: 23277361]
19. Scherder E, Bouma A, Borkent M, Rahman O. Alzheimer patients report less pain intensity and pain affect than non-demented elderly. *Psychiatry*. 1999; 62:265–272. [PubMed: 10612117]
20. Scherder E, Herr K, Pickering G, Gibson S, Benedetti F, Lautenbacher S. Pain in dementia. *Pain*. 2009; 145:276–278. [PubMed: 19409705]
21. Benedetti F, Vighetti S, Ricco C, et al. Pain threshold and tolerance in Alzheimer's disease. *Pain*. 1999; 80(1–2):377–382. [PubMed: 10204751]
22. Benedetti F, Arduino C, Vighetti S, Asteggiano G, Tarenzi L, Rainero I. Pain reactivity in Alzheimers patients with different degrees of cognitive impairment and brain electrical activity deterioration. *Pain*. 2004; 111:22–29. [PubMed: 15327805]
23. Rainero I, Vighetti S, Bergamasco B, Pinessi L, Benedetti F. Autonomic responses and pain perception in Alzheimer's disease. *Eur J Pain*. 2000; 4:267–274. [PubMed: 10985870]
24. Kunz M, Mylius V, Scharmann S, Schepelman K, Lautenbacher S. Influence of dementia on multiple components of pain. *Eur J Pain*. 2009; 13:317–325. [PubMed: 18562225]
25. Pickering G, Jourdan D, Dubray C. Acute versus chronic pain treatment in Alzheimer's disease. *Eur J Pain*. 2006; 12:379–384. [PubMed: 16087372]
26. Kunz M, Scharmann S, Hemmeter K, Lautenbacher S. The facial expression of pain in patients with dementia. *Pain*. 2007; 133:221–228. [PubMed: 17949906]
27. Gibson S, Voukelatos X, Ames D, et al. An examination of pain perception and cerebral event-related potentials following carbon dioxide laser stimulation in patients with Alzheimer's disease and aged-matched control volunteers. *Pain Res Manag*. 2001; 6:126–132. [PubMed: 11854775]
28. Scherder E, Eggermont L, Plooijs B, et al. 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(1):50–58. [PubMed: 18185014]
29. Monroe T, Carter M. A retrospective pilot study of African-American and caucasian nursing home residents with dementia who died from cancer. *J Pain Symptom Manage*. 2010; 40(4):e1–e3. [PubMed: 20817471]
30. Monroe T, Carter M, Feldt K, Tolley B, Cowan RL. Assessing advanced cancer pain in older adults with dementia at the end-of-life. *J Adv Nurs*. 2012; 68:2070–2078. [PubMed: 22272816]
31. Morrison RS, Magaziner J, McLaughlin MA, et al. The impact of post-operative pain on outcomes following hip fracture. *Pain*. 2003; 103:303–311. [PubMed: 12791436]
32. Morrison RS, Siu AL. A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip Fracture. *J Pain Symptom Manage*. 2000; 19:240–248. [PubMed: 10799790]
33. Cadogan MP, Schnelle JF, Yamamoto-Mitani N, Cabrera G, Simmons SF. A minimum data set prevalence of pain quality indicator: is it accurate and does it reflect differences in care processes? *J Gerontol A Biol Sci Med Sci*. 2004; 59:M281–M285.
34. Herr K, Coyne P, McCaffery M, Manworren R, Merkel S. Pain assessment in the patient unable to self-report: position statement with clinical practice recommendations. *Pain Manag Nurs*. 2011; 12:230–250. [PubMed: 22117755]

35. Cadogan MP, Schnelle JF, Al-Sammarrai NR, et al. A Standardized Quality Assessment System to Evaluate Pain Detection and Management in the Nursing Home. *J Am Med Dir Assoc.* 2006; 7:S11–S19. [PubMed: 16500269]
36. Chu L, Schnelle JF, Cadogan MP, Simmons SF. Using the minimum data set to select nursing home residents for interview about pain. *J Am Geriatr Soc.* 2004; 52:2057–2061. [PubMed: 15571542]
37. Kölzsch M, Wulff I, Ellert S, et al. Deficits in pain treatment in nursing homes in Germany: a cross-sectional study. *Eur J Pain.* 2012; 16:439–446. [PubMed: 22337470]
38. Monroe TB, Mion LC. Patients with advanced dementia: how do we know if they are in pain? *Geriatr Nurs.* 2012; 33:226–228. [PubMed: 22657833]
39. Monroe TB, Herr KA, Mion LC, Cowan RL. Ethical and legal issues in pain research in cognitively impaired older adults. *Int J Nurs Stud.* 2013; 50:1283–1287. [PubMed: 23245707]
40. U. S. Department of Health Human Services. Minimum Data Set (MDS) Version 2.0. 2000 Jul 12.2008
41. Morris J, Brant E, Fries D, et al. MDS cognitive performance scale. *J Gerontol.* 1994; 49:m174–m182. [PubMed: 8014392]
42. Stevenson KM, Brown RL, Dahl JL, Ward SE, Brown MS. The discomfort behavior scale: a measure of discomfort in the cognitively impaired based on the minimum data set 2.0. *Res Nurs Health.* 2006; 29:576–587. [PubMed: 17131282]
43. Mor V, Angelelli J, Jones R, Roy J, Moore T, Morris J. Inter-rater reliability of nursing home quality indicators in the U.S. *BMC Health Serv Res.* 2003; 3:1–13.
44. Hawes C, Morris J, Phillips C, Mor V. Reliability estimates for the minimum data set for nursing home resident assessment and care screening (MDS). *Gerontologist.* 1995; 35:172–179. [PubMed: 7750773]
45. Morris JN, Fries BE, Morris SA. Scaling ADLs within the MDS. *J Gerontol A Biol Sci Med Sci.* 1999; 54(11):M546–M553. [PubMed: 10619316]
46. Gruber-Baldini AL, Zimmerman SI, Mortimore E, Magaziner J. The validity of the minimum data set in measuring the cognitive impairment of persons admitted to nursing homes. *J Am Geriatr Soc.* 2000; 48:1601–1606. [PubMed: 11129749]
47. Paquay L, De Lepeleire J, Schoenmakers B, Ylief M, Fontaine O, Buntinx F. Comparison of the diagnostic accuracy of the Cognitive Performance Scale (Minimum Data Set) and the Mini-Mental State Exam for the detection of cognitive impairment in nursing home residents. *Int J Geriatr Psychiatry.* 2007; 22:286–293. [PubMed: 17022109]
48. Weiner DK, Rudy TE. Attitudinal barriers to effective treatment of persistent pain in nursing home residents. *J Am Geriatr Soc.* 2002; 50:2035–2040. [PubMed: 12473018]
49. Herr K. Pain Assessment Strategies in Older Patients. *J Pain.* 2011; 12(3 Suppl):S3–S13. [PubMed: 21396599]
50. Takai Y, Yamamoto-Mitani N, Chiba Y, Nishikawa Y, Hayashi K, Sugai Y. Abbey Pain Scale: Development and validation of the Japanese version. *Geriatr Gerontol Int.* 2010; 10:145–153. [PubMed: 20446928]
51. Monroe TB, Carter MA, Feldt KS, Dietrich MS, Cowan RL. Pain and hospice care in nursing home residents with dementia and terminal cancer. *Geriatr Gerontol Int.* 2013

Table 1Study sample characteristics overall and by dementia status ($n = 52$)

Characteristic	Total sample ($n = 52$)	Dementia ($n = 20$)	Non-dementia ($n = 32$)	<i>P</i> -value
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
Sex				0.350
Female	35 (67.3)	15 (75.0)	20 (62.5)	
Male	17 (32.7)	5 (25.0)	12 (37.5)	
Race/ethnicity				0.160
White	37 (71.2)	12 (60.0)	25 (78.1)	
Black	15 (28.8)	8 (40.0)	7 (21.9)	
Depression diagnosis				0.202
Absent	24 (46.2)	7 (35.0)	17 (53.1)	
Present	28 (53.8)	13 (65.0)	15 (46.9)	
Age	Median (IQR)	Median (IQR)	Median (IQR)	0.080
Years	84.0 (78–90)	86.5 (80–93)	83.0 (76–87)	
	Min = 51, Max = 99	Min = 74, Max = 94	Min = 51, Max = 99	
Length of stay				0.566
Months	10.4 (1.6–24.8)	14.5 (1.8–27.2)	9.6 (1.6–23.7)	
	Min = 1, Max = 179	Min = 1, Max = 103	Min = 1, Max = 179	
Total no. pain diagnoses				0.565
	4.0 (2–4)	4.0 (2–4)	3.5 (2–5)	
	Min = 1, Max = 7	Min = 1, Max = 6	Min = 1, Max = 7	
Activities of Daily Living Scale				0.087
	17.0 (13–21)	16.0 (12–20)	18.0 (14–22)	
	Min = 5, Max = 28	Min = 5, Max = 27	Min = 7, Max = 28	
Cognitive Performance Scale				0.001
Levels of cognitive impairment	3.0 (2–3)	3.0 (3–3)	2.0 (1–3)	
	Min = 0, Max = 4	Min = 2, Max = 4	Min = 0, Max = 3	

IQR, interquartile range; Max, maximum; Min, minimum.

Table 2Pain orders ($n = 52$)

Variable	Total sample ($n = 52$)	Dementia ($n = 20$)	Non-dementia ($n = 32$)	P-value
	n (%)	n (%)	n (%)	
Prescription type [†]				0.003
Opioid only	8 (15.4)	5 (25.0)	3 (9.4)	
Non-narcotic only	18 (34.6)	11 (55.0)	7 (21.9)	
Both	26 (50.0)	4 (20.0)	22 (68.8)	
Administration frequency				0.586
Scheduled only	3 (5.8)	2 (10.0)	1 (3.1)	
PRN only	19 (36.5)	7 (35.0)	12 (37.5)	
Both	30 (57.7)	11 (55.0)	19 (59.4)	

[†]Non-narcotic versus opioid/both. Odds ratio 4.37, 95% confidence interval 1.29–14.73, $P = 0.018$. PRN, *pro re nata*.

Table 3Pain interview response ($n = 45$)

Characteristic	Total sample ($n = 45$)	Dementia ($n = 19$)	Non-dementia ($n = 26$)	<i>P</i> -value
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
Do you have pain right now?				
Yes	25 (55.6)	11 (57.9)	14 (53.8)	0.787
	Median (IQR)	Median (IQR)	Median (IQR)	
If yes, how much on a 0–10 scale?	$n = 22$	$n = 9$	$n = 13$	0.010
0 = no pain to 10 = severe pain	7.0 (4.7–8.3)	8.0 (7.0–9.5)	6.0 (4.0–7.0)	
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	
Do you have pain everyday?				
Yes	30 (66.7)	12 (63.2)	18 (69.2)	0.670
Does pain keep you from sleeping at night?				
Yes	25 (55.6)	13 (68.4)	12 (46.2)	0.138
Does pain keep you from doing the things that you enjoy? [†]				
Yes	28 (63.6)	12 (66.7)	16 (61.5)	0.728
Do you tell nurse about pain?				
Yes	40 (88.9)	15 (78.9)	25 (96.2)	0.070
Does nursing staff ask you about pain?				
Yes	34 (75.6)	12 (63.2)	22 (84.6)	0.098
Would you prefer to take meds for pain? [†]				
Yes	37 (84.1)	15 (83.3)	22 (84.6)	0.909
Probable chronic pain				
Yes	23 (51.1)	11 (57.9)	12 (46.2)	0.436

[†]Total $n = 44$, dementia $n = 18$, non-dementia $n = 26$.