

Characteristics Associated With Pain in Long-Term Care Residents With Dementia

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This article describes the prevalence, assessment, and treatment of pain, as well as characteristics associated with pain, in 331 residents with dementia in 45 assisted living facilities and nursing homes. Overall, 21% of residents had pain, and pain was more commonly reported in for-profit facilities, and for those receiving professional assessment and treatment.

Key Words: *Discomfort, Cognitive impairment, Nursing homes, Assisted living, Residential care*

Pain is common in residents of long-term care facilities, with prevalence estimates in nursing homes ranging from 49% to 83% (Fox, Raina, & Jadad, 1999). Pain leads to negative consequences, including impaired mobility, depression, and social withdrawal (Ferrell, 1991; Ferrell, Ferrell, & Osterweil, 1990; Parmelee, Katz, & Lawton, 1991); for those with dementia, pain may exacerbate cognitive decline and

agitated behavior (Buffum, Miaskowski, Sands, & Brod, 2001; Feldt, Warne, & Ryden, 1998). Pain is likely no less common in those with dementia than in the cognitively intact (Farrell, Katz, & Helme, 1996), although it is less frequently reported (Cohen-Mansfield & Lipson, 2002; Parmelee, Smith, & Katz, 1993; Sengstaken & King, 1993) and treated (Horgas & Tsai, 1998; Morrison & Siu, 2000). Reputed causes of underdetection include inability of residents with dementia to communicate their discomfort verbally (Weissman & Matson, 1999); lack of staff training (Ferrell, 1995; Weissman & Matson) and formal assessment (Weiner, 2002); and staff attitudinal barriers (Mrozek & Werner, 2001; Weiner & Rudy, 2002). Though challenging, particularly in noncommunicative demented residents, standardized assessment is recommended (Ferrell, 1995; Weiner). Once pain is identified, treatment should be administered, using both pharmacologic and nonpharmacologic approaches (AGS Panel on Persistent Pain in Older Persons, 2002; Ferrell, 1995).

While the process of pain care for cognitively impaired nursing home residents has received some research attention, less work has focused on pain in demented individuals in residential care/assisted living (RC/AL). Furthermore, existing research provides little understanding of factors that are associated with staff reporting of resident pain in both types of long-term-care settings. Therefore, this study has two objectives: (a) describe the prevalence and relevant components of pain management in nursing homes and RC/AL; and (b) identify resident and facility characteristics associated with staff reports of pain in individuals with dementia.

Methods

Sample

As part of the Dementia Care project of the Collaborative Studies of Long-Term Care, (Zimmerman et

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al., 2005, this issue), residents aged 65 and older with diagnosed dementia were randomly selected from each of 10 nursing homes and 35 RC/AL facilities in four states. The participation rate was 73% among eligible residents; a total of 421 residents were enrolled. These analyses are based on the 331 residents for whom the care supervisor provided pain data. The care supervisors in this study were predominantly nurses (77% were registered nurses [RNs] or licensed practical nurses [LPNs]), and most (75%) had been in their current position for at least one year.

Measures

Pain was measured using the Philadelphia Geriatric Center–Pain Intensity Scale (PGC–PIS; Parmelee et al., 1991), and the 0–10 pain numeric rating scale (NRS; Jensen & Karoly, 1992). For these analyses, residents scoring 2 or more on the PGC–PIS (range 1 = no pain to 5 = extreme pain) are considered to have pain. This threshold corresponds to an average across the six items of “a little” pain or worse; all residents meeting this definition had a response of “moderate” pain or worse on at least one item. Both instruments were administered to the supervisor overseeing each resident’s care (for all participants) and to those residents who scored 10 or greater on the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). The PGC–PIS had excellent internal consistency reliability for both supervisor and resident samples (Cronbach’s $\alpha = 0.89, 0.88$, respectively). Both also correlated well with the NRS (Spearman $r = 0.69$, supervisor; $r = 0.68$, resident).

In accordance with the conceptual framework of structure, process, and outcome (Donabedian, 1980) as operationalized for this study, supervisors were administered a series of questions regarding pain assessment, treatment, and training. They reported perceived presence of pain in the past week (“a moderate amount” or more) and formal pain assessment in the past year (written, standardized assessment and/or by physician or nurse). Treatment included ongoing professional treatment, other treatment (including informal), and treatment success among residents with pain in the past year (with “quite” or “extremely” well constituting “perceived success”). Staff also reported perceived training adequacy (with “quite” or “extremely” well trained in identifying and helping with resident physical pain and discomfort classified as feeling adequately trained). Facility administrators reported on facility demographic characteristics and estimated the proportion of supervisory and direct care staff who received formal training in detecting and treating pain.

Resident cognition was assessed using the MMSE and the Minimum Data Set Cognition Scale (MDS-COGS; Hartmaier, Sloane, Guess, & Koch, 1994). Functional status was measured with the MDS-ADL (Morris, Fries, & Morris, 1999), and comorbidity as the number of 10 supervisor-reported conditions (detailed in Table 1). Residents were classified as having arthritis based on supervisor report of resident

arthritis, rheumatism, degenerative joint disease, lupus erythematosus, or scleroderma.

Current medication use was ascertained by asking the supervisor to list all prescription and nonprescription medications used four or more days in the prior week. Residents taking one or more analgesics, anti-pyretics, nonsteroidal anti-inflammatory drugs (NSAIDs), and/or narcotics were identified as receiving pain medication. Aspirin was excluded because most aspirin use in long-term care is for cardiovascular disease prevention and is at a dosage that is sub-therapeutic for pain.

Analysis

Descriptive statistics were computed separately for RC/AL facilities and nursing homes, with statistical comparison of settings for these characteristics computed using Generalized Estimating Equations (GEE; Diggle, Heagerty, Liang, & Zeger, 2002), applied to linear or logistic (for continuous and binary characteristics, respectively) models and adjusting for participant clustering by facility. Descriptive statistics were similarly computed for those for whom the supervisor reported pain and those without pain. Odds ratios and 95% confidence intervals were estimated using separate logistic regression models for each characteristic, controlling for clustering using GEE empirical standard error estimates and exchangeable correlation. Adjusted odds ratios were estimated controlling for resident age, gender, non-White race, cognitive impairment, comorbid conditions, and activities of daily living (ADL) dependencies. To ensure that factors associated with pain did not differ between nursing homes and assisted living facilities, a setting-by-characteristic interaction term was tested in each multivariable logistic model.

Results

Among the 331 residents for whom the supervisor reported on pain, the average age was 84.4 years, 82% were female, and 11% non-White. Ninety-two (27.8%) residents were sufficiently cognitively intact (MMSE ≥ 10) to report their own pain.

Table 1 describes the pain status of the sample. None of the measures of pain prevalence differ significantly between nursing home and RC/AL residents. Based on supervisor report, 20% to 23% had pain; among residents who self-reported, the prevalence was higher (25% to 39%). For residents with both supervisor and self-report, there was 62% agreement ($\kappa = 0.10$) for the presence of pain (PGC–PIS ≥ 2).

More than one third of residents (34.7%) had no formal pain assessment. Formal assessment, all types of pain treatment, and staff training in assessment and treatment were all reported more often by nursing homes than RC/AL facilities. More than three fourths of supervisors in both settings reported success in treating resident pain and more than 90% reported

feeling adequately trained to identify and help with resident pain.

When associations between resident characteristics and pain were evaluated (Table 2), depression and arthritis were identified as significant, independent correlates of pain. No association was noted between resident cognitive status and supervisor pain report.

When facility factors were related to pain status, residents in for-profit facilities were found to be more likely to have supervisors reporting resident pain, an effect undiminished by covariate adjustment. To explore this finding, we examined whether other aspects of pain care differed between profit and nonprofit facilities. In these post hoc analyses, we found that residents in for-profit facilities were less likely to undergo professional pain assessment (54% vs 81%, $p = .008$). Also, fewer residents in for-profit homes were receiving pain medication, both overall (34% vs 61%, $p = .015$) and among those with pain (53% vs 91%, $p = .041$). Consequently, when the association between for-profit status and pain was adjusted for professional assessment and medication use, along with the other covariates, the relationship strengthened (AOR = 4.3, 95% CI 1.8–10.1).

Other statistically significant associations noted between facility factors and reported pain included professional assessment and all forms of pain treatment. Still, one quarter of those with pain had not been professionally assessed, 60% had not received a standardized assessment, and 19% of residents with pain were receiving neither pain medication nor ongoing professional treatment. Treatment was less likely to be perceived as successful in those in whom current pain was reported (AOR = 0.4, 95% CI 0.2–0.8). No interactions between resident or facility characteristics and setting (nursing home vs RC/AL facility) were statistically significant (all $p > .05$).

Discussion

We found few differences in pain prevalence and components of pain management between nursing homes and RC/AL facilities, the notable exception being that more nursing home residents received pain treatment, especially medications. Roughly 40% of residents with pain in both settings were receiving no pain medication and nearly one third (31.3%) were receiving no treatment for pain. Given the Joint Commission on Accreditation of Healthcare Organizations' mandate for regular pain assessment in nursing homes (Phillips, 2000), it is notable that a substantial minority of residents received no formal pain assessment and that assessment was only slightly more common in nursing homes than RC/AL facilities.

The prevalence of pain reported here, whether by resident or supervisor report (20% to 39%) appears lower than the frequently cited prevalence of up to 80% in previous nursing home studies. However, this disparity is due at least in part to our use of a threshold of 2.0 to denote pain, rather than a broader definition of "any" pain. Applying the latter criterion to our

Table 1. Prevalence of Pain and Relevant Components of Care in Dementia Care Study Sample, by Setting

	M (SD) or %		<i>p</i> ^a
	RC/AL (<i>n</i> = 222)	NH (<i>n</i> = 109)	
Pain			
Prevalence			
Supervisor report			
Residents with pain (PGC-PIS ≥ 2) ^b	20.3	22.9	0.741
PGC-PIS	1.5 (0.6)	1.6 (0.6)	0.439
Pain Numeric Rating Scale (0–10)	1.1 (1.8)	0.9 (1.5)	0.718
Resident report ^c			
Residents with pain (PGC-PIS ≥ 2) ^b	38.9	25.0	0.318
PGC-PIS	1.9 (0.9)	1.6 (0.6)	0.228
Pain Numeric Rating Scale (0–10)	2.5 (3.0)	2.3 (2.6)	0.776
Assessment			
Professional	57.7	73.8	0.373
Written or standardized	28.6	55.1	0.076
Perceived presence, current	9.5	8.3	0.732
Treatment			
Professional	31.4	43.0	0.092
Informal	39.1	51.9	0.068
Current nonaspirin pain medication	34.4	58.9	0.008
Perceived success (if perceived pain; quite a bit or extremely)	78.5	78.9	0.764
Training to detect and treat^d			
Supervisory staff			
None in facility	21.2	0.0	—
Some in facility	23.1	32.1	—
Most in facility ($\geq 75\%$)	55.8	67.9	0.443
Direct care providers			
None in facility	43.3	11.0	—
Some in facility	19.7	19.3	0.266
Most in facility ($\geq 75\%$)	37.0	69.7	0.042
Staff feels adequately trained to assess	94.6	94.5	0.853
Staff feels adequately trained to treat	92.8	93.6	0.717

Notes: RC/AL = residential care/assisted living; NH = nursing home; PGC-PIS = Philadelphia Geriatric Center-Pain Intensity Scale. Except as noted for training, all data are resident level, are of those for whom outcome data (i.e., pain) were available, and, except for the Resident report of prevalence of pain, are from supervisor report. Due to missing data, *n* of supervisor data varied from 209 to 222 (RC/AL) and 107 to 109 (NH), except "perceived success of treatment," which was relevant only for those perceived to have had pain in the past year and for whom there were data—121 (55%) and 76 (70%) RC/AL and NH participants, respectively.

^aAdjusted for facility-level clustering using generalized estimating equations (GEE; exchangeable correlation matrix); *p* values are based on score statistics.

^bPain as per supervisor or resident report using the PGC-PIS.

^cData from resident interview (*n* = 72 RC/AL, 20 NH).

^dData regarding supervisory staff training and direct care provider training (first two items) are facility level and reported by administrators. Staff feelings of training adequacy were reported by the one supervisor (or direct care provider, if supervisor data are unavailable) who was most involved in the resident's care; "adequately" is quite or extremely well trained.

sample, the prevalence is 62% and 76% for supervisor and resident report, respectively. Further, our supervisor and resident mean PGC-PIS scores (1.53 and 1.80,

Table 2. Characteristics Associated With Substantial Pain, Unadjusted and Adjusted

Characteristics	Distribution of Characteristic as % or M (SD)		Relationship Between Characteristics and Presence of Pain	
	No Pain (PGC-PIS < 2)	Pain (PGC-PIS ≥ 2)	Unadjusted OR (95% CI)	Adjusted ^a OR (95% CI)
Resident^b				
Cognitive status				
Mildly impaired	12.0	16.4	1.00	1.00
Moderately impaired	27.5	22.4	0.66 (0.27, 1.65)	0.50 (0.18, 1.38)
Severely impaired	23.3	28.4	1.03 (0.36, 2.89)	0.86 (0.27, 2.72)
Very severely impaired	37.2	32.8	0.76 (0.30, 1.96)	0.50 (0.15, 1.70)
Depressed	18.6	41.8	2.32 (1.13, 4.77)	2.91 (1.18, 7.21)
Behavioral symptoms	57.0	62.7	1.06 (0.49, 2.29)	1.16 (0.57, 2.36)
Low activity	49.8	33.8	0.65 (0.38, 1.11)	0.64 (0.37, 1.10)
Immobile	12.3	12.5	1.06 (0.49, 2.29)	0.79 (0.37, 1.69)
Low food intake	52.9	53.0	1.18 (0.64, 2.17)	1.03 (0.56, 1.87)
Low fluid intake	49.6	53.2	1.20 (0.67, 2.15)	1.14 (0.66, 1.99)
Arthritis	29.8	47.8	2.36 (1.45, 3.87)	2.02 (1.19, 3.42)
Facility				
Facility type				
Nursing home	31.8	37.3	1.00	1.00
RC/AL, < 16 beds	12.0	20.9	1.37 (0.44, 4.23)	1.45 (0.46, 4.59)
RC/AL, Traditional	24.8	17.9	0.50 (0.18, 1.44)	0.67 (0.22, 2.08)
RC/AL, New-model	31.4	23.9	0.54 (0.12, 2.31)	0.60 (0.15, 2.46)
Facility size (OR per 10 beds)	87.6 (53.4)	87.7 (52.0)	0.99 (0.91, 1.08)	0.99 (0.91, 1.07)
For-profit ownership	66.5	83.6	2.83 (1.34, 6.01)	2.99 (1.40, 6.39)
Assessment of pain				
Professional	59.9	75.0	2.61 (1.42, 4.79)	2.56 (1.37, 4.78)
Written or standardized	36.9	39.1	1.06 (0.59, 1.90)	1.01 (0.55, 1.84)
Perceived presence, current	1.6	37.3	23.31 (9.45, 57.5)	26.63 (8.82, 80.4)
Treatment of pain				
Professional	25.9	68.7	5.65 (3.62, 8.82)	5.43 (3.32, 8.87)
Informal	34.4	73.1	5.17 (2.87, 9.34)	5.39 (2.97, 9.80)
Current nonaspirin pain medication	37.9	59.7	2.85 (1.63, 5.00)	2.89 (1.53, 5.47)
Perceived success (if perceived in pain)	85.4	64.5	0.39 (0.18, 0.84)	0.39 (0.18, 0.84)
Training to detect and treat pain^c				
Supervisory staff				
None in facility	9.4	27.3	1.00	1.00
Some in facility	29.4	16.7	0.24 (0.06, 1.00)	0.22 (0.05, 1.03)
Most in facility (≥ 75%)	61.2	56.1	0.41 (0.13, 1.31)	0.41 (0.13, 1.30)
Direct care providers				
None in facility	28.6	45.5	1.00	1.00
Some in facility	23.3	6.1	0.20 (0.06, 0.64)	0.20 (0.06, 0.67)
Most in facility (≥ 75%)	48.2	48.5	0.65 (0.26, 1.63)	0.58 (0.25, 1.35)
Staff feels adequately trained to assess	93.8	97.0	1.61 (0.75, 3.46)	1.42 (0.59, 3.45)
Staff feels adequately trained to treat	94.6	88.1	0.41 (0.16, 1.07)	0.48 (0.16, 1.41)

Notes: PGC-PIS = Philadelphia Geriatric Center-Pain Intensity Scale. For the table, $N = 325$; pain: $n = 67$; no pain: $n = 258$. Pain was assessed by supervisor report using the PGC-PIS, and “pain” refers to a score of 2 or more. Except as noted for training, all data are resident level, are of those for whom outcome data (i.e., pain) were available, and were from supervisor report. Due to missing data, n varied from 310 to 325, except in the case of “perceived success of treatment”, which was relevant only for those perceived to have had pain in the past year and for whom there were data—192 (59%) participants.

^aAdjusted for male gender, non-White race, age, cognitive status, number of 10 comorbidities (congestive heart failure; high blood pressure; myocardial infarction, angina, arrhythmias, or other heart problems; diabetes; kidney disease or renal insufficiency; fractured bones or osteoporosis; cerebrovascular disease, stroke, TIA, or CVA; hemiplegia or paraplegia; asthma, emphysema, bronchitis, or COPD; schizophrenia, manic-depressive disorder, or mental retardation), and impairments in seven activities of daily living (bed mobility, transfer, locomotion, dressing, eating, toilet use, hygiene).

^bCognitive status is based on Mini-Mental State Examination (MMSE) or Minimum Data Set-Cognition (MDS-COGS) scores, if the MMSE is missing ($n = 51$). Cutpoints for mild, moderate, severe, and very severe (MMSE) are ≥ 17 , 10–16, 3–9, 0–2; MDS-COGS cutpoints are 0–1, 2–4, 5–6, 7–10. Depressed: ≥ 7 on the Cornell Scale for Depression in Dementia; low activity: < 9 on the Albert Patient Activity Scale; behavioral symptoms: any behaviors at least weekly on the Cohen-Mansfield Agitation Inventory; immobile: no position or location changes observed during 3 hours of observation; low food intake and low fluid intake: consumed $\leq \frac{3}{4}$ of meal and drank ≤ 8 oz. on Structured Meal Observation. Arthritis: arthritis, rheumatism, degenerative joint disease, lupus erythematosus, or scleroderma. Depression, behavioral symptoms, and arthritis were from supervisor report; activity was from care provider report; and immobility and consumption were based on direct observation.

^cData regarding supervisory staff training and direct care provider training (first two items) were facility level and reported by administrators. Staff feelings of training adequacy were reported by the one supervisor (or direct care provider, if supervisor data are unavailable) who was most involved in the resident’s care; “adequately” is quite or extremely well trained.

respectively) are remarkably similar to those for markedly impaired (1.47) and cognitively intact (1.80) groups previously reported (Parmelee et al., 1993). Finally, analgesic use—commonly used as an indirect measure of pain—was similar in our study (34% to 59%) to the prevalence reported in a recent review (Fox et al., 1999).

We found pain more common in for-profit facilities, independent of resident demographics and health status. This could be because more residents in for-profit facilities have pain or simply because their pain is more frequently recognized. The fact that both professional assessment and pain medication use are less common in for-profit facilities makes the latter explanation less plausible, however, and suggests a need for more assessment and care in these facilities.

We used proxy report as the primary pain measure. For the 27% of residents who administered a self-reported pain measure, agreement with the supervisor was modest, albeit similar to (Werner, Cohen-Mansfield, Watson, & Pasis, 1998) or better than (Horgas & Dunn, 2001; Weiner, Peterson, Ladd, McConnell, & Keefe, 1999) that reported by others. While a potential study limitation, proxy report allowed the standardized assessment of pain using a reliable, valid pain instrument (Parmelee, 1994; Parmelee et al., 1991; Parmelee et al., 1993) for the entire sample of cognitively impaired long-term-care residents (mean MMSE = 8.1). In fact, a recent study found that correlation between caregiver and care-recipient pain report was stronger for the PGC-PIS than for other pain measures examined (Krulwich et al., 2000). The great majority (84%) of supervisors had known the residents for whom they reported pain for at least a year, and 88% reported that they knew the residents “pretty well” or “very well.” Further, proxy report is salient because recognition of pain by staff is an essential first step in its effective management (Kamel, Phlavan, Malekgoudarzi, Gogel, & Morley, 2001), and we wished to identify correlates of this important endpoint. While it is not surprising that pain was noted in those for whom current treatment is reported, the finding that treatment is less likely to be deemed successful in those with pain suggests that staff are cognizant of the residents for whom pain management remains incomplete. This finding may be considered in conjunction with the very high proportion of staff who report feeling adequately trained to assess and treat pain in the residents under their care, perhaps implying that some staff are unaware of other techniques to treat pain or feel that additional intervention is either not warranted or unavailable.

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