EXTRA Dementia and Geriatric Cognitive Disorders

Dement Geriatr Cogn Disord Extra 2015;5:470–481
DOI: 10.1159/000441717
Published online: December 5, 2015

1664–5464/15/0053–0470$39.50/0
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Original Research Article

The Quality of Pain Treatment in Community-Dwelling Persons with Dementia

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Key Words

Dementia · Pain management · Quality indicators, health care · Veterans

Abstract

Background/Aims: Despite pervasive and debilitating pain among elders, it is underassessed and undertreated; and cognitive impairment can add challenges. We assessed the quality of pain care for community-dwelling elderly patients with dementia. ***Methods:*** We phone interviewed 203 Veterans Affairs primary care outpatients with dementia and pain and reviewed medical records to score 15 quality indicators of pain assessment and management. ***Results:*** Pain assessment was documented for 98%, and a standard pain scale was used for 94%. Modified pain scales were rarely used. Though 70% self-reported pain of 'quite bad' or worse, charts documented no pain in 64%. When pain was identified, treatment was offered to 80%; but only 59% had a follow-up assessment within 6 months. Nonpharmacological interventions were underused. ***Conclusion:*** Community-dwelling elders with dementia are underdiagnosed and undertreated for pain.

Trial registration (parent study): NCT01325714 in ClinicalTrials.gov (http://clinicaltrials.gov/ct2/results?term=Preventing+aggression+in+veterans+with+dementia&Search=Search).

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Introduction

Pain is pervasive and debilitating among older people. An estimated 25–50% of elders in the community, and 40–80% of elders in nursing homes, suffer from pain or pain-related conditions [1, 2]. Although pain has recently received increased clinical, policy, and research emphasis, the focus has largely been on developing assessment methodologies, with little attention to assessing quality of pain care [3, 4]. What is clear is that older adults are still underassessed and undertreated for pain; up to a quarter of adults aged 50 years and older report unalleviated pain in the last 2 years of life, and 46% report unalleviated pain in the last month of life, independent of the cause of death [5]. Community-dwelling elders, in particular, are at increased risk of pain, attributable to suboptimal prescribing and lack of access to care [6–8].

In addition, 3–11% of individuals over 65 years and 20–50% of individuals over 85 years suffer from cognitive impairment, which can deprive individuals of the ability to recall and characterize pain [9]. Unfortunately, self-report remains the mainstay of modern pain assessment, making it difficult for providers to accurately assess pain in dementia patients, using conventional methods [10]. Despite efforts to create behaviorally based pain assessment tools (Doloplus-2 [11], PACSLAC [12], and NOPPAIN [13]), their adoption by clinicians has been limited [2, 14]. Older adults with dementia are, thus, at higher risk for additional underassessment and undertreatment of pain than their cognitively intact, same-aged cohorts [15].

Despite recognition of these gaps in care, little work has examined the quality of pain assessment and treatment in vulnerable elders [16]. The Assessing Care Of Vulnerable Elderly (ACOVE) quality indicators are a standardized measure used and validated in multiple studies for quality of care assessment of various medical conditions, based on interviews, medical-records review, or both [17–23]. Validity has also been demonstrated in elders with dementia [24]. Developed to assess various areas of care in the elderly [25], ACOVE quality indicators include specific items for pain management (11 in total, 8 with demonstrated validity) [1]. However, the application of ACOVE measures to quality of pain management in older individuals with dementia has not been previously explored. A meta-analysis of 41 studies using ACOVE found only two focused on patients with dementia, with both looking only at whether the indicators were applicable [26].

As the majority of cognitively impaired older individuals reside in the community [2], and as they are one of the most at-risk groups for poor pain management because of barriers in access and inconsistency in quality of caregiving [27, 28], assessment of their quality of pain care is much needed. This study used established quality indicator items, including ACOVE quality indicators, to attempt to fill the gap in knowledge regarding quality of pain care in outpatient older adults with dementia. We abstracted medical-record data to investigate multiple facets of pain care quality for persons with dementia, including actual clinical practices, medication administration, details of pain assessment, and utilization of nonpharmacological interventions.

Methods

Participants and Data Collection

Participants in this analysis were enrolled in a randomized controlled trial of the effectiveness of a pain treatment intervention for elderly individuals with both pain and dementia. All had dementia and pain affecting their functioning enough to merit interest in an 8-week psychosocial intervention. Trial participants were identified by (a) a search of the Veterans

Affairs (VA) Outpatient Data for persons with a diagnosis of dementia or (b) an active prescription of a VA class CN900 medication for dementia or (c) a provider referral to the study. Inclusion criteria included (1) a documented diagnosis of dementia in patients aged 60 years and older; (2) receipt of primary care from the Veterans Health Administration; (3) residence outside a long-term care facility; (4) residence within 50 miles of the Michael E. DeBakey VA Medical Center in Houston, Tex.; (5) mild-to-moderate dementia [defined as having a Functional Assessment Staging (FAST) stage of 2–6]; (6) no history of aggression in the past year; (7) having a caregiver who can reliably report the Veteran's status by spending a minimum of 8 h per week, at least twice a week, with the Veteran and is able to speak English, and (8) a positive pain screen through self-report and a caregiver's confirmation.

Baseline Assessment

As part of the larger trial, participants completed a phone-based baseline assessment that recorded demographics, primary caregiver relationships, pain, and psychosocial and functional status. Interviews took place between September 2011 and January 2014.

The interview included one item from the Philadelphia Geriatric Pain Intensity Scale that assessed for worst pain [29]. Participants were asked: 'Now, thinking about the past several weeks, please rate how bad your pain was when it was at its worst'. Caregivers were asked the same question, reworded in the third person. Response options for both groups were 'no pain', 'little pain', 'moderate pain', 'quite bad pain', 'very bad pain', or 'the pain is almost unbearable'. The scale was presented as a thermometer graphic in which higher temperatures were associated with greater pain. The graphic was mailed to participants before the baseline phone assessment. This item has been associated with psychosocial outcomes in prior research [30].

Participants were also assessed using the FAST [31], a clinician-rated measure of functional decline in dementia. It is a continuous scale, ranging from 1 to 7, with higher stages indicating greater cognitive impairment. The FAST is the best-validated rapid measure to place patients along a spectrum of cognitive decline, with demonstrated reliability and validity [29, 32–34]. It incorporates clinical observations and parts of commonly used mental assessment tools, such as several sevens to elicit the stage of a patient's cognitive decline in dementia [35]. Only participants in stages 2–6 were eligible to participate in the parent study; thus, participants represented the range of dementia severity.

Medical Records Review Using Quality Indicators

The ACOVE quality indicators (accessible at www.annals.org) were developed and screened by expert panel reviews and widely used in quality-of-care studies [18]. A total of 236 ACOVE quality indicator items covers a spectrum of medical conditions, including quality indicators for pain management used in this study. Additional pain quality assessment items adapted by Cadogan et al. [21] were based on ACOVE quality indicators for osteoarthritis, as well as Minimum Data Set quality indicators for pain assessment in nursing homes. These items were included to increase the comprehensiveness of quality assessment. Osteoarthritis items were included, in particular, as it is the most common source of pain among elderly individuals [36].

Medical records were collected from VA Outpatient Data records from 6 months before to 6 months after (12 months total) each person's baseline assessment. Abstracted records included notes from primary care, geriatric outpatient clinics, nursing, and mental health/psychiatric outpatient clinics. Physical therapy notes were documented as evidence for referral to physical therapy. All medical reviews were performed by a trained research assistant, guided by written abstraction guidelines and on-site consultation from a geriatric psychiatrist. Reliability was tested through reabstracting 10 randomly selected medical

records for consistency. The total number of records abstracted per person, total number of records assessing pain per person, and total number of records using a standardized scale per person were documented. Records were examined for level of detail of pain assessment (e.g. type, intensity, location of pain) and type of pain scale used (e.g. 0–10 scale, behavioral assessment scale), especially if any modifications of pain scales for cognitive impairment were made. The level of pain reported in the record closest to the baseline assessment date (within 60 days before or after the baseline date) was also documented.

All qualifying records were considered when determining whether a person was eligible for and received care that met criteria for each quality indicator item. Certain items applied to and were scored for only a subset of participants (e.g. items on osteoarthritis). If a person was eligible for and had care that met the criteria for a quality indicator, a score of '1' was given; otherwise, a '0' was given.

The quality of medication administration was also examined. All medications either formally prescribed or documented as being taken were considered during abstraction. Medication lists were taken from the record closest in time to the baseline assessment date. Pain medications were separated into three classes, based on the World Health Organization's Analgesic Ladder [nonsteroidal anti-inflammatory drugs (NSAIDs)/acetaminophen, weak opioids, and strong opioids], and were noted as being administered as needed or on a scheduled basis. The resulting data were used to create dichotomous variables, with '1' indicating the presence of a pain medication within each category during the abstraction period and '0' indicating no pain medication in that period. Records of participants taking NSAIDs were examined for documentation of the absence of peptic ulcer disease or justification for the use of an NSAID. Records of persons over the age of 75 years on a non-COX-2 inhibitor NSAID with a history of peptic ulcer disease, gastrointestinal bleeds, or warfarin were examined for administration of a proton pump inhibitor. If a person was on opioids, records were examined for coadministration of a laxative. Avoidance of meperidine was also examined, as its use poses many risks and is generally discouraged.

New chronic pain diagnoses based on ICD-9-CM codes for one or more of the following pain diagnoses were noted within the abstraction period: arthropathies, osteoarthritis, and related disorders (710–719); dorsopathies (720–724); rheumatism, excluding the back (725–729); osteopathies, chondropathies, and acquired musculoskeletal deformities (730–739); headache (307.81, 339, 346, 784.0); gout (274), and other pain disorders [i.e. generalized pain (780.96); pain disorders related to psychological factors (307.8), and pain not elsewhere classified (338)]. The presence of osteoarthritis was determined based on the presence of a diagnosis any time before the end of the abstraction period.

Records for persons diagnosed with new chronic pain were examined for documentation of an evaluation for depression or changes in mood within 1 month of pain presentation. Records for this subgroup also were examined for documentation of a targeted (defined as having a documented assessment of the painful area) physical and history performed within 1 month of pain presentation. To determine whether treatment was offered for a new painful condition, records were examined for discussion of therapy (either pharmacological or nonpharmacological). For persons given treatment, records were examined for a reassessment within 6 months of the presentation of pain.

For persons with osteoarthritis, records were examined for at least one assessment of osteoarthritic pain and functionality of the affected location within the 12-month abstraction period. Whether the first medication given for osteoarthritis was acetaminophen was also documented, even if the first chart documenting this was outside the abstraction period and not exclusively outpatient. Likewise, all available records were examined to determine whether acetaminophen dosage was increased to a maximum dose of 4 g before switching to another medication.

Records were also examined for referral to specialty pain clinics, rheumatology clinics, specialty mental health treatment and physical therapy, and documentation of discussions on pain education, exercise, and the availability of community resources and support groups.

Statement of Ethics

This study was approved by the institutional review boards of the Michael E. DeBakey VA Medical Center and Baylor College of Medicine. Participants provided informed consent.

Results

Of the trial participants who met all criteria (n = 213), 10 were excluded for either dying within 6 months of completing the baseline assessment or for not having documented outpatient notes in the VA system. Record review was performed on the remaining 203 participants. Ages ranged from 61 to 95 years (SD = 8.2). Most patients were identified as 'not white'. Just under half reported an annual income of less than USD 20,000, and 66% identified a spouse as the primary caregiver. Education level was represented across the spectrum. The entire spectrum of dementia was represented, and just over half represented a FAST stage of 6. The distribution of pain from 'moderate' to 'almost unbearable' was well represented, and 70% reported worst pain of 'quite bad' or greater. The entire spectrum of pain interference with daily life was also represented, with a majority reporting that pain interfered with daily life (table 1).

A total of 1,365 records were reviewed, with an average of 6.7 per person. Medical records closest to the baseline index date indicated that 63.6% reported no pain (table 2). Forty percent were not taking any type of pain medication. Of 121 individuals receiving medication for pain, 32.5% were taking an NSAID or acetaminophen, 16.8% were taking weak opioids, 1.5% were taking strong opioids, and 8.9% were taking other pain medications (e.g. capsaicin patches, gabapentin) (table 3).

An assessment of pain was documented for 199 (98%) individuals; and, on average, 88% of each participant's records were assessed for pain (table 4). A standardized self-report-based pain assessment scale was used to assess 191 (94%) individuals; and, on average, 66% of each person's records were assessed, using a pain scale (table 5). Pain scales modified for cognitive impairment were used for 4 (2%) individuals. A new pain condition was reported by 151 (74%) individuals. Of these, a targeted physical was offered within 1 month to 87 (58%), while a history was taken from 82 (54%). Treatment was offered to 121 (80%), and 71 (59%) treated persons received a follow-up assessment within 6 months. A new chronic pain diagnosis was identified in 91 (45%), and 32 (35%) received an evaluation for depression and mood changes within 1 month of presentation of pain.

Osteoarthritis was reported in 107 individuals, with 64 (60%) using pain medication as treatment. Of these 64 patients, 49 (77%) were treated first with acetaminophen. Of 35 individuals not currently being treated for osteoarthritis with acetaminophen, the maximum dose of acetaminophen (4 g/day) had been tried and documented for 13 (37%). Of 19 individuals prescribed an NSAID for the treatment of pain of any type, 3 (16%) had either documentation of the absence of peptic ulcer disease or a justification for NSAID use in place of alternative forms of treatment. Ten were over the age of 75 years, treated with a non-COX-2 inhibitor NSAID, and had a history of peptic ulcer disease, gastrointestinal bleeding, or current warfarin usage. Three (30%) of these patients were offered treatment with a proton pump inhibitor. Of 55 individuals treated with an opioid, 23 (42%) were offered a laxative. Meperidine was not used for any of the 203 persons. Use of specialty clinics and nonpharmacological interventions was also reported (table 6).

Table 1. Demographic characteristics of study participants

Variables	Study participants, % (n = 203)
Gender	
Male	98.5
Female	1.5
Age, years[a]	78.9±8.2
Race	
White	48.8
Not White	51.2
Ethnicity	
Hispanic or Latina	14.0
Not Hispanic or Latina	86.0
Caregiver relationship	
Spouse	66.0
Son/daughter	22.6
Sibling	1.5
Other relative	6.9
Friend	1.0
None of the above	0.50
Did not answer	1.50
Education	
Did not complete high school	15.8
High school graduate or GED	31.5
Some college	25.6
Four-year college degree	17.7
Graduate or professional degree	6.9
Did not answer	2.5
Income	
USD <10,000	4.9
USD 10,000–19,999	36.9
USD 20,000–29,999	25.6
USD 30,000–39,999	12.8
USD 40,000–49,999	6.9
USD 50,000–59,999	1.5
USD ≥60,000	3.5
Did not answer	7.9
Functional status (FAST[b])	
Stage 2: possible mild cognitive impairment	0.5
Stage 3: mild cognitive impairment	2.5
Stage 4: mild dementia	23.8
Stage 5: moderate dementia	21.2
Stage 6: moderately severe dementia	52.0
Worst pain	
No pain	6.0
Little	9.0
Moderate	24.6
Quite bad	20.1
Very bad	25.6
Almost unbearable	14.7
To what extent does pain interfere with daily life?	
Not at all	33.3
A little	16.7
Some	22.2
Quite a bit	18.2
A great deal	7.6
n.a.	2.0

GED = General Education Development; n.a. = not applicable. [a] Mean ± SD is used for age. [b] FAST is a dementia staging system focused on an individual's level of functioning and activities of daily living.

Table 2. Degree of pain documented in the medical chart closest to baseline assessment (n = 203)

Pain level	%
Little to no pain (0)	63.6
Mild pain (NRS 1–3; VDS 1–2; faces 1–2)	14.3
Moderate pain (NRS 4–7; VDS 3; faces 3)	17.2
Severe pain (NRS 8–10; VDS 4–6; faces 4–6)	4.9

NRS = Numerical Rating Scale; VDS = Verbal Descriptor Scale.

Table 3. Strength of current pain medication (n = 203)

Medication type	%	Total, %
NSAID/acetaminophen, PRN	30.0	
NSAID/acetaminophen, scheduled	2.5	32.5
Weak opioid, PRN	13.8	
Weak opioid, scheduled	3.0	16.8
Strong opioid, PRN	0.5	
Strong opioid, scheduled	1.0	1.5
Other	8.9	
No pain medication prescribed or reported	40.3	

PRN = As needed.

Table 4. ACOVE quality indicators for pain management

Quality indicators	n	Passed, %
All vulnerable elders should be screened for pain	203	98.0
If an elder has osteoarthritis, functionality/pain should be assessed annually	107	78.9
If an elder has a new pain condition, a targeted physical should be offered in 1 month	151	57.6
If an elder has a new pain condition, a history should be offered in 1 month	151	54.3
If an elder reports a new painful condition, then treatment should be offered	151	80.1
If an elder is treated for a pain condition, then s/he should be reassessed within 6 months	121	58.7
If an elder has been prescribed an NSAID for the treatment of pain, then the medical record should indicate whether s/he has a history of peptic ulcer disease, and if a positive history is present, justification of NSAID use in place of an alternative therapy should be documented	19	15.8
If an elder over age 75 years is being treated with a non-COX-2 inhibitor NSAID and has any of the following: history of peptic ulcer disease, history of gastrointestinal bleed, or current warfarin use, then s/he should be offered treatment with misoprostol or a proton pump inhibitor	10	30.0
If an elder requires analgesia, then meperidine should not be used	203	100.0
If an elder with pain is treated with opioids, then s/he should be offered a bowel regimen or the medical record should document the potential for constipation and/or explain why bowel treatment is not needed	55	41.8

Discussion

In general, pain assessment was consistently performed in cognitively impaired older individuals; but follow-up steps in management, including offering treatment, histories, physicals, and follow-up appointments, were much less frequently performed. However, rates of meeting ACOVE quality indicators for these follow-up steps are consistent with rates found in previous studies [1, 37]. Though recent guidelines have encouraged clinicians to be more

Table 5. ACOVE quality indicators for osteoarthritis and Minimum Data Set quality indicators for pain (modified by Cadogan et al. [21])

Quality indicators	n	Passed, %
If an elder has pain or is diagnosed with chronic pain, then s/he should be evaluated for depression by a primary care physician within 1 month	91	35.2
If an elder is screened for pain, then a quantitative pain assessment using a standard pain scale should be used (with its use not precluded but modified for cognitive impairment)	203	94.1
If a patient has cognitive impairment, pain scales should be appropriately modified (e.g. measure behavioral characteristics)	203	2.0
If oral pharmacologic therapy is initiated to treat symptomatic osteoarthritis, then acetaminophen should be the first drug used	64	76.6
If oral pharmacologic therapy for symptomatic osteoarthritis is changed from acetaminophen to a different agent, then there should be evidence that the elder has had a trial of maximum dose acetaminophen	35	37.1

Table 6. Use of specialty clinics and nonpharmacological resources (n = 203)

Type of resources	% used
Pain clinic	3.0
Rheumatology clinic	1.5
Physical therapy	19.2
Pain education	29.6
Exercise	45.8
Psychiatric therapy	41.9
Community resources	17.2

attentive to pain screening, this has yet to translate into the next step in similar improvements in treatment and follow-up [38–40].

We found comparable rates in the use of quantitative pain assessment scales as previous studies (94 vs. 90% noted in Cadogan et al. [21]) but found that scales used were almost completely self-report (94%) and not suitable for our patients who all have baseline dementia. This is reflected in our finding that clinicians, as documented in medical records, reported less pain than patients did via our detailed self- or caregiver-assisted assessments via phone interview (63.6% medical records reported no pain compared with 6% reporting no pain via self-assessment). This sizable discrepancy echoes previous findings that the magnitude of underassessment and undertreatment of pain directly correlates with the severity of dementia and the accuracy with which clinicians can detect pain via conventional means [15]. Additionally, providers have been shown by prior studies to document pain only when patients can verbalize and rate their own pain, which patients with dementia often cannot do [41–43]. The slow adoption of alternative methods of pain assessment outside the self-report 0–10 Numerical Rating Scale creates the issue of inaccurate assessment for cognitively vulnerable patients, which is partially attributed to the lack of a unified opinion on the use of relatively new nonverbal pain assessment tools [2, 44].

Providers adhered to defined medication administration guidelines (e.g. acetaminophen as first treatment of osteoarthritis, avoidance of meperidine) but were less attentive to avoiding polypharmacy and side effects, paralleling previous quality-of-care studies in osteoarthritis that found higher pass rates of quality indicators for treatment than adherence to medication safety [45]. Physicians tend to overlook follow-up of medications, such as moni-

toring side effects and patient education, leading to low rates of administration of laxatives with opioids, documentation of peptic ulcer disease with NSAID usage, and follow-up appointments [37].

In general, prescription rates for opioids were lower than for NSAIDs and acetaminophen, supporting prior findings that clinicians are more hesitant to prescribe opioids for chronic pain for persons with cognitive impairment [46, 47]. However, while opioids carry well-known risks, they still have an important role in pain relief and are likely being underused in individuals with dementia [48]. Acetaminophen can be inefficacious for moderate-to-severe pain and further contribute to pain undertreatment [49]. In addition, it is contraindicated in persons with liver metabolism issues, a not infrequent condition in frail, elderly persons. Opioids do not have liver toxicity issues, and evidence suggests that they also reduce agitation in persons with severe dementia [50]. However, self-administration of pain medication in cognitively impaired patients presents its own set of risks, especially in light of our findings that most patients were prescribed NSAIDs/acetaminophen on an as-needed basis, which is difficult for cognitively impaired older patients. Mezinskis et al. [51] demonstrated that a third of patients in a nursing home receiving assistance for as-needed pain medication did not receive any doses.

Finally, nonpharmacological pain interventions, with recommendations for exercise being the exception, were underused. Exercise was recommended at a rate consistent with US Center for Disease Control statistics [52]. Few studies have examined the prevalence of physician referrals to community resources and support groups; but these resources will play an important role in improving delivery of high-quality medical care, particularly for chronic diseases [53].

This study is among the first to examine the quality of pain assessment and management in community-dwelling elders with dementia, but it has several limitations. As our participants all received care at the Veterans Health Administration, they were mostly men with a background in military service. However, prevalence rates of medical factors, such as arthritic pain and chronic pain medication use, closely reflect those of the general population [54, 55]. Much of our data comes from medical records, so we included phone interview data for a more comprehensive assessment. Finally, the number of thoroughly examined quality indicators for pain management is small and can be highly specific. However, ACOVE quality indicators are the gold standard of quality assessment, and their frequent use in quality-of-care studies creates a standardized platform facilitating comparison of results [25, 56]. Still, one glaring omission in the ACOVE quality indicators is detailed examinations of nonpharmacological therapies. Many dementia specialists recommend that nonpharmacological interventions be trialed simultaneously or before pharmacologic interventions [57]. Our examination of other resources used for pain management indicates that the use of nonpharmacological approaches needs much improvement, and we look forward to more careful tracking of these approaches.

In conclusion, elderly persons with dementia risk being underdiagnosed and undertreated for pain; and community-dwelling persons with dementia face additional barriers against successful pain assessment. These stem from the lack of pain recognition and underuse of appropriate assessment tools, and, when pain is identified, from discrepancies in following certain medication best practices and from the extremely low use of nonpharmacological interventions for pain. Although current guidelines have reinforced the importance of assessing for pain and treating when pain is detected, more needs to be done to ensure assessment is done accurately and treatment is implemented with the person's long-term well-being in mind. In addition, nonpharmacological interventions, including pain education, exercise, and community resources, should be emphasized and more successfully integrated into clinical practice to create an overall higher quality of medical care.

Acknowledgement

This paper is the result of work supported by the Department of VA, Veterans Health Administration, Office of Research and Development (grant IIR 009-351) and the Houston VA Health Services Research and Development Center for Innovations in Quality, Effectiveness and Safety (CIN13-413). The views expressed reflect those of the authors and not necessarily those of the Department of VA, the US government or Baylor College of Medicine.

Disclosure Statement

None of the authors reports a financial conflict of interest.

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DOI: 10.1159/000441717

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