

Correlates of Pain Intensity in Community-Dwelling Individuals With Mild to Moderate Dementia

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Abstract

Objectives: To identify correlates of participant-reported pain in community-dwelling individuals with mild to moderate dementia. **Methodology:** Associations among participant-reported pain intensity and depressive symptoms, mental health diagnoses, pain diagnoses, pain medications, level of functional ability, and cognitive impairment were assessed in 136 community-dwelling veterans with mild to moderate dementia and pain. Univariate and multiple regressions were used to assess relationships among the independent variables and participant-reported pain. **Results:** Pain diagnoses ($\beta = .23$, $t_{132} = 2.65$, $P < .01$) and pain medications ($\beta = .21$, $t_{132} = 2.48$, $P < .05$) were correlated with participant-reported pain intensity in univariate regression models. Only pain diagnoses ($\beta = .20$, $t_{132} = 2.17$, $P < .05$) remained a significant predictor in adjusted models. **Conclusion:** Participant-reported pain in individuals with dementia appears to be a unique construct for which other psychosocial indicators cannot be substituted. Therefore, directly asking community-dwelling individuals with mild to moderate dementia about their pain is a critical component of assessment.

Keywords

pain, dementia, depression, assessment, community dwelling

Introduction

Dementia affects between 3 and 4 million older adults in the United States, and that number is expected to increase dramatically as the US population ages.^{1,2} Pain is common in those with dementia,^{3,4} and functional impairments due to pain become more severe over the life span.⁵ Unfortunately, pain is often undertreated in adults with dementia for a number of reasons, including the fact that dementia-associated deficits in memory, language, and abstract thinking can lead to inaccurate reports of pain. In addition, it can be difficult for others to identify pain in this population, as individuals with dementia often present with complex manifestations of pain due to multiple comorbidities and altered behavior patterns (eg, vocalizations, fidgeting, increased movement, and decreased movement) that could indicate many forms of distress, including depression, boredom, anxiety, or pain.⁶ Some of these issues can be addressed by observational measures of pain; however, the problem of behavioral overlap remains a limitation. Once pain is identified, clinicians and caregivers may be reluctant to engage in pain treatment because of higher rates of treatment complications among individuals with dementia.⁵ Further complicating matters, time-pressed practice environments often necessitate the

quick evaluation of pain at a single time point, a potentially problematic practice, given that pain is an experience that unfolds and changes over time, especially in populations with dementia.⁷

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Identifying correlates of pain in community-dwelling individuals with mild-to-moderate dementia could provide researchers, clinicians, and caregivers with heuristics to improve the identification of those at risk of pain or those with undertreated pain in a population that cannot always accurately and effectively communicate internal experiences. To date, most research on the assessment of pain in persons with dementia has focused on older adults living in long-term care facilities, where pain and pain-related behaviors can be observed over long periods of time. These findings suggest that depression is associated with self- and proxy-reported pain⁸⁻¹³ and that poor physical functioning may be associated with pain (possibly through an interaction between pain and depression).^{9,10} Less research has focused on correlates of pain in nonresidential populations with dementia, where pain assessments may be time limited. The results of such studies are mixed. Some have found an association between depression and self- and proxy-reported pain in community-dwelling older adults.¹⁴⁻¹⁷ However, others have found associations between such factors only in unadjusted models (eg, depression did not predict pain in adjusted models¹⁸) or have found no association between psychosocial patient factors (eg, mental status, mood, function, education, and aggression) and self- or proxy-reported pain.¹⁹ Given the dearth of research in nonresidential populations with dementia, the mixed results of existing research, and the difficulties inherent in assessing pain in individuals with dementia, further investigation is warranted.

The objective of the current study was to extend findings by confirming or refuting potential correlates of participant-reported pain in community-dwelling persons with mild-to-moderate dementia. We examined the associations between participant-reported pain intensity and the following patient factors: depressive symptoms, mental health diagnoses, pain diagnoses, pain medications, level of functional ability, and cognitive impairment. Based on the fact that a slightly greater number of studies report associations between psychosocial factors and pain, it was hypothesized that a greater number of depressive symptoms, mental health diagnoses, pain diagnoses, pain medications, and functional disability would each be associated with greater participant-reported pain intensity.

Methods

Participants

Data came from baseline assessments of 136 veterans, all of whom were enrolled in a randomized controlled trial of a pain treatment intervention for individuals with pain and any form of dementia (described elsewhere).²⁰ All participants had mild to moderate dementia and pain that affected their functioning enough to merit interest in an 8-week psychosocial intervention. Potential participants were identified through (1) provider referral; (2) Veterans Administration (VA) Outpatient Data Files in which a diagnosis of dementia was represented by the *International Classification of Diseases, Ninth Revision, Clinician Modification (ICD-9-CM)* codes: 290, 294, 313; and/or

(3) the presence of a VA class CN900 medication for dementia (donepezil, galantamine, memantine, or rivastigmine), as indicated in VA Decision Support System pharmacy files. Potential participants received opt-out letters; and follow-up screening calls determined whether veterans met the following inclusion criteria: (1) documented diagnosis of dementia; (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, Texas, USA; (5) mild to moderate dementia; (6) no history of aggression in the past year; (7) having a caregiver who is directly involved with the veteran at least 8 hours per week, sees the veteran at least twice a week, and speaks English; and (8) clinically significant pain, indicated by the caregiver's answering affirmatively to a pain screening question or the participant's rating his or her pain at the level of 2 or higher on the Philadelphia Geriatric Pain Intensity Scale,²¹ which corresponds to "a little pain" or worse. Veterans who met criteria and agreed to participate in the study completed written consent forms and a phone-based baseline assessment from which the data for this study have been taken.

Measures

All measures were kept as brief as possible so as to minimize the burden on participants with cognitive deficits.

Participant- and caregiver-reported worst pain. One continuous item from the Philadelphia Geriatric Pain Intensity Scale²¹ was used to capture participant- and caregiver-reported worst pain. 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 also asked to report the pain they perceived in participants, using this item. The item was chosen because it has been associated with psychosocial outcomes in prior research.¹⁵ Participants and caregivers answered the question on a 6-point scale: "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. The thermometer graphic yields a higher response rate than either the Faces Scale or a Visual Analog Scale in individuals with dementia.²² In analyses, higher scores indicated worse pain (range of possible scores: 0-5).

The Short Blessed test. Participants completed the Short Blessed,²³ which is a 6-item, validated measure used to assess cognitive impairment. It was derived from the full Blessed test. The Short Blessed is a continuous measure, with greater scores indicating greater cognitive impairment. In the current study, the scale had adequate internal consistency (Cronbach's $\alpha = 0.73$).²³

Participant characteristics. Data were collected on age as a continuous variable. Gender and race (white or not white) were

collected as dichotomous variables. Patient characteristics were obtained via participant and caregiver report.

Geriatric Depression Scale. The Geriatric Depression Scale²⁴ (GDS) is a 30-item measure designed to assess depression in geriatric populations. Higher scores indicate a greater number of depression symptoms. Scores on the GDS range from 0 to 30, and scores ≥ 10 are a possible indicator of depression. Analyses used the dichotomous classification of the GDS such that “1” indicated the presence of depression (GDS scores ≥ 10), and “0” indicated no depression (GDS scores < 10). The GDS is validated for use in individuals with dementia^{24,25} and for use with collaterals over the phone.²⁶ Due to concerns about respondent burden for participants with dementia, as well as concerns about the underreporting of depression in some dementia populations,²⁷ caregivers answered items as the veterans’ proxies. For the study sample, the scale had good internal consistency (Cronbach’s $\alpha = 0.87$).

Functional Assessment Staging. The Functional Assessment Staging (FAST)²⁸ is 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 combines clinical observation with informant data and has demonstrated reliability and validity.²⁸ Only participants in stages 2 to 6 were eligible to participate in the parent study; thus, all participants had mild-to-moderate dementia.

Pain diagnoses. *International Classification of Diseases, Ninth Revision, Clinician Modification* codes, based on prior research,²⁹ were used to identify participants with at least one of the following pain diagnoses within the year prior to the baseline assessment: arthropathies 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 (ie, generalized pain [780.96]; pain disorders related to psychological factors [307.8]; and pain not elsewhere classified [338]). The resulting data were used to create a dichotomous variable, with “1” indicating the presence of at least 1 pain diagnosis within the year prior to the baseline assessment and “0” indicating no pain diagnoses in that time period. Data were extracted from VA Outpatient Data Files.

Prescriptions for pain medications. Data from VA Decision Support System Pharmacy Files were used to determine whether a participant received a prescription for at least a 30-day supply of analgesics during the year before participants’ baseline assessment. Medications included narcotic analgesics (VA Class CN101, CN102) and nonnarcotic analgesics (VA Class CN100, CN103, CN104, CN105, MS000, MS101, or MS102), such as aspirin, acetaminophen, naproxen, piroxicam, buprenorphine, codeine, morphine, methadone, and oxycodone. The resulting data were used to create a dichotomous variable, with “1” indicating the presence of a pain medication

within the year prior to the baseline assessment and “0” indicating no pain medication in that time period.

Mental health diagnoses. Data from VA Outpatient Data Files were used to identify participants’ diagnoses of depression, anxiety, and/or posttraumatic stress disorder (PTSD) within the year prior to the baseline assessment. Posttraumatic stress disorder was separated from other anxiety disorders, given its high prevalence in veteran populations. Diagnoses were categorized using the following *ICD-9-CM* codes: depression (293.83, 296.20-296.36, 300.4, 311), anxiety (293.84, 293.89, 300.00-300.02, 300.09, 300.20-300.23, 300.29, 300.3), and PTSD (308, 309.81). The resulting data were used to create a dichotomous variable, with “1” indicating the presence of depression, anxiety, and/or PTSD in the year prior to baseline assessment and “0” indicating no diagnosis of depression, anxiety, or PTSD in that time period.

Data Analyses

Univariate linear regression was used to assess relationships between each independent variable (ie, participant characteristics, depressive symptoms, mental health diagnoses, pain diagnoses, pain medications, level of functional ability, and cognitive impairment) and the dependent variable, participant-reported worst pain. Variables with a $P \leq .25$ in the univariate regressions were included in a multiple linear-regression model, as previous work has demonstrated that using lower α levels often fails to identify variables known to be important.³⁰ Variables were examined to assure that regression colinearity assumptions were met using tolerance (TOL) and variance inflation factor (VIF) statistics (TOL values $< .10$ and VIF values > 10 were used to indicate colinearity among predictors). The white test was used to test for homoscedasticity. All analyses were conducted in SAS version 9.3 (SAS Institute, Cary, North Carolina).

Results

Almost all participants were men (97%). Half were caucasian, and the mean age was 79.64 years (standard deviation [SD] = 7.97). On the basis of FAST scores, 67 (50%) participants had moderately severe dementia (stage 6), 25 (18%) had moderate dementia (stage 5), and 43 (32%) had mild dementia or cognitive impairment (stages 2-4). Mean scores on the Short Blessed test also suggested that all participants were cognitively impaired (mean [M] = 13.98, SD = 6.12). Most (77%) participants scored above 10 (the clinical cutoff) on the GDS: 22 (16%) participants scored in the severe range (20-30), 81 participants (61%) scored in the mild range, and 31 participants (23%) scored in the normal range. On the basis of data from outpatient files, 41 (30%) participants had a diagnosis of depression, 12 (9%) had an anxiety disorder diagnosis, and 9 (7%) had a PTSD diagnosis within 1 year of baseline.

The mean rating of worst pain was approximately “quite bad pain” (M = 2.82, SD = 1.48), and 84 (62%) participants

had at least 1 pain diagnosis within a year of the baseline assessment. In all, 67 (49%) participants had at least one 30-day prescription for a pain medication in that same time period (55 [40%] had a prescription for a nonnarcotic analgesic, and 12 [9%] had a prescription for a narcotic analgesic).

Results of univariate regression analyses indicated that having a pain diagnosis ($\beta = .23$, $t_{132} = 2.65$, $P < .01$) and having a prescription for a pain medication ($\beta = .21$, $t_{132} = 2.48$, $P < .05$) were associated with worse participant-reported pain over the past several weeks. Univariate analyses for age ($\beta = .10$, $t_{132} = -1.16$, $P = .25$), level of functional ability ($\beta = .12$, $t_{131} = -1.37$, $P = .17$), and cognitive impairment ($\beta = .12$, $t_{131} = -1.36$, $P = .18$) were significant at $P \leq .25$ and were therefore retained in the multiple regression model. No other variables (depressive symptoms, mental health diagnoses, and race) were significantly correlated with participant-reported worst pain.

The multiple regression analysis included participant-reported worst pain as the dependent variable and the following independent variables: having a pain diagnosis within the past year; having a prescription for pain medication within the past year; age; level of functional ability; and cognitive impairment. All variables had low VIF values (1.1-1.4) and high TOL values (0.73-0.93), which indicated that colinearity would not affect analyses. The white test for heteroscedasticity was not significant ($P = .70$), indicating that residual variance was homogeneous. Results of the multiple regression analysis suggest that having at least 1 pain diagnosis within the past year was the only significant and unique correlate of participant-reported worst pain ($\beta = .20$, $t_{132} = 2.17$, $P < .05$).

We considered the possibility that some of the null findings were due to disparate sources of information, as the caregiver reported the veteran's depressive symptoms, whereas the veteran reported pain intensity. We conducted a post hoc analysis, in which all previous univariate associations were retested, using caregiver ratings of participant worst pain as the dependent variable. Again, a multiple regression model was used to test variables with univariate P values $\leq .25$. Similar results were obtained. In univariate models, only pain diagnosis ($\beta = .26$, $t_{134} = 3.09$, $P < .005$) and a prescription for pain medication ($\beta = .27$, $t_{134} = 3.19$, $P < .005$) were correlated with caregiver reports of participants' worst pain over the past several weeks. The multiple-regression analysis assessing relationships among caregiver ratings of participants' worst pain included pain diagnoses and pain medication as independent variables (no other variables in univariate models were associated with caregiver-reported participant worst pain at $P \leq .25$). Both pain diagnosis ($\beta = .22$, $t_{134} = 2.65$, $P < .005$) and pain medications ($\beta = .23$, $t_{134} = 2.77$, $P < .005$) were significant and unique correlates of caregiver reports of participants' worst pain in this multiple regression model.

Discussion

The data presented here are some of the first to report on correlates of pain in community-dwelling individuals with

dementia, and the findings add to the growing body of literature on the topic. As expected, pain diagnoses and prescriptions for pain medications were associated with greater participant-reported pain in veterans with mild to moderate dementia. However, only pain diagnoses were associated with greater participant-reported pain in the adjusted model. Supporting previous research,^{8,10,19} demographic variables (age, sex, and race) were not associated with participant reports of pain. Contrary to previous reports,⁸⁻¹³ depressive symptoms, mental health diagnoses, and level of functional ability were not associated with participant-reported worst pain, demonstrating that community-dwelling adults with dementia can experience pain in the absence of mood and/or functional disturbances. As such, these factors may not be accurate heuristics for self-reported worst pain in this population.

The lack of correlation between participant-reported pain and depression is surprising, as it differs from results of studies in residential^{8,11,13} and community-dwelling^{15,17} populations with dementia. One possible explanation is that individuals with dementia living in the community are more resilient than those in long-term care; for example, depression may be more prevalent and/or more severe among nursing-home residents.³¹ Perhaps more compelling is the possibility that a single self-rating of worst pain does not provide sufficient information about the overall experience of pain—a dynamic experience that occurs over days, weeks, and months. As such, study designs and pain assessments may need to account for variance in pain over time by using multiple assessments, a technique that has been successfully piloted in community-dwelling individuals with dementia.^{7,32} It may also be that self-report alone is not sufficiently sensitive and, thus, behavioral observation ratings should supplement self-report ratings.

Rating pain at multiple time points may be particularly important when assessing pain in individuals with dementia, as cognitive ability and subsequent accuracy of ratings can be affected by environmental factors (eg, time of day). Additional support for this hypothesis comes from the fact that many studies reporting a correlation between pain and depression had longitudinal designs, included those without dementia, and/or included multiple pain assessments (see eg,^{8,10-12,15}). Furthermore, at least 1 study that assessed pain at a single time point also found no relationship between pain and depression in individuals with dementia.¹⁹ Therefore, additional research comparing the efficacy and accuracy of single versus multiple pain ratings may be necessary before drawing final conclusions regarding heuristics for pain in this population. It is important to publish null results related to both assessment techniques, as the reporting of such results will allow researchers and clinicians to understand both effective and ineffective assessment procedures.

The current study has both limitations and strengths. The largest limitation is the cross-sectional nature of the study, which precludes conclusions regarding causation or temporal relationships among variables. Other limitations include a restricted range of cognitive impairment; the brevity of some assessment measures; the fact that we could not distinguish

between acute, chronic, and procedural pain; and a lack of female participants. In addition, these findings are based on data drawn from a larger trial of a pain intervention; as such, we cannot compare these findings with those that might be found in a sample of older adults with pain and without dementia. However, the study's strengths include a diverse sample and the systematic identification of individuals with dementia, as recommended by the VA Dementia Registry Consensus Work Group.³³

In summary, the current data suggest that patients with dementia experience pain, regardless of depressive symptoms, mental health diagnoses, or functional status. As such, the results do not support the use of patient-level, psychosocial variables as heuristics for participant-reported worst pain in community-dwelling individuals with dementia. The obvious conclusion is that directly asking about for pain is an important assessment endeavor in this population. We posit that collecting repeated self-report assessments and/or collecting behavioral ratings may be techniques for further improving assessment quality.

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Declaration of Conflicting Interests

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