

## Identification, assessment, and management of pain in patients with advanced dementia

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### Abstract

Patients with advanced dementia have a high symptom burden at end of life. Many of those with dementia have reports of symptoms similar to those without dementia, yet are treated less frequently. Pain is a prevalent symptom that can be underrecognized because of the ability of the patient to self-report. Several tools are available to help with the identification of pain, but they should only be one aspect in the overall assessment. Health care providers must anticipate this and screen for and treat potential pain. This includes obtaining a self-report, searching for potential causes for pain, observing patient behavior, gaining proxy reporting of pain, and attempting an appropriate analgesic trial. It is beneficial for all those involved with a patient's care to screen for pain because of the potential benefits in decreasing behaviors and subsequent antipsychotic use.

**Keywords:** dementia, pain, pain assessment, end-of-life

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experienced by patients with advanced dementia will be addressed in this article.

### Symptoms in End-Stage Dementia

Patients with advanced illnesses, including end-stage dementia, experience a high symptom burden.<sup>1</sup> Pinzon et al<sup>7</sup> described the most common symptoms experienced by patients with dementia in comparison with patients without dementia in the 2 days prior to death. The prevalence of physical symptoms was similar for weakness (94.9% and 92.8%, with and without dementia, respectively), fatigue (94.4% and 90.3%), appetite loss (86.4% and 85.5%), dyspnea (56.7% and 62.9%), constipation (38.3% and 35.9%), and vomiting (17.3% and 22.3%). However, the presence of reported pain was statistically less in patients with dementia compared with those without (52.5% and 62.7%, respectively;  $P < .05$ ), as was the complaint of nausea (26.4% and 37.6%, respectively;  $P < .01$ ). There was, however, a large disparity in the prevalence of disorientation and confusion between these two populations (86.9% for dementia patients and 41.0% for patients without dementia;  $P < .001$ ).<sup>7</sup> The authors

### Introduction

Dementia is defined as a neurocognitive disorder with many different subtypes in which 60% to 80% of cases are given a diagnosis of Alzheimer dementia.<sup>1</sup> Although Alzheimer disease is not a diagnosis generally thought of as life-limiting or fatal, Alzheimer disease is the fifth leading cause of death in the United States, with 1 in 3 patients receiving a diagnosis being 85 years or older.<sup>1</sup> Despite the prevalence, dementia remains a less common admitting diagnosis to hospice care compared with cancer.<sup>2,3</sup> Hospice has a great opportunity to provide benefits to these patients with symptom burden. Family members of those who elect hospice report enhanced patient quality of life.<sup>2,4-6</sup> A review of pain symptoms, assessment, and an approach to the treatment of pain



hypothesized that lower reporting of pain and nausea was unsurprising because these are subjective complaints and may be underreported in patients with disorientation and confusion, which is consistent with other literature as discussed below.<sup>7,8</sup> In summary, end-stage dementia is a symptom-burdensome disease.

## Behaviors in Patients With Dementia

Patient behaviors may be correlated with the presence of pain in cognitively impaired individuals. When used in this context, “behaviors” refers to inappropriate, repetitive, or dangerous behaviors that are disruptive to the living and working environment (usually consisting of wandering, aggression, and agitation).<sup>9-12</sup> These behaviors are frequent in patients with dementia in the nursing home, where 40% to 60% of patients wander and 50% to 80% of patients display aggression or agitation.<sup>13,14</sup>

Pain has been positively associated with behaviors. They can look different depending on the baseline of the patient. Some suggest that pain may reduce wandering, likely because of pain upon movement, whereas aggressive and agitated behavior may result in increased wandering.<sup>15,16</sup> Therefore, changes in baseline behaviors can be important indicators for pain prevalence. Agitation and aggression are most commonly treated with antipsychotics, such as haloperidol, quetiapine, and risperidone. These mediations come with significant risks, including increased mortality in elderly patients with dementia-related psychosis. Studies have shown that the use of pain medication significantly reduces antipsychotic use.<sup>17,18</sup> The reduction in antipsychotic use is of significant interest within nursing homes because of regulations that are in place to limit antipsychotic use.

## Pain in Patients With Dementia

Recent studies suggest the prevalence of pain in dementia patients is approximately 50%; however, this may be a low estimation.<sup>7,8</sup> Many barriers exist that contribute to underreporting of pain, including the lack of pain management education, the failure to use a standardized pain assessment tool, inadequate documentation, resident inability to communicate pain, resident reluctance to report pain, perceptions of use of strong pain medication, and regulatory concerns.<sup>19-23</sup>

Literature suggests patients with dementia thought to have pain or a painful condition received opioid analgesics 67% less often, and 45% did not receive treatment at all in comparison with those without dementia.<sup>24,25</sup> The ability to self-report is the “gold standard” for pain assessment, which, as previously stated, can be a barrier in patients with dementia. Dementia impairs the ability to remember,

interpret, and respond to pain. This results in the gradual loss of the ability to process information. Therefore, patients are less likely to express pain in typical ways, even when there is a probable cause for pain.<sup>26,27</sup> Some atypical presentations of pain could include agitation, aggression, wandering, and calling out. Some of the contributing factors to atypical pain presentation are in relation to motivational-affective changes in patients with dementia.<sup>28,29</sup> Affective-motivational responses to pain include the innate response for pain avoidance or motivation to terminate the painful experience.<sup>30</sup> This translates to a patient perceiving that sitting on a wound or in a painful position is painful. A patient with an intact affective-motivational response would move and avoid sitting in that position in the future. Those with decreased affective-motivational response to pain would continue to sit in that position and continue to experience pain. As a result, these protective responses may be reduced in patients with dementia because of changes within the medial pain system, which mediates the affective-motivational response.<sup>30</sup>

Although patients with dementia can express and perceive pain differently, they are often plagued by painful conditions similarly to those without dementia. A study conducted by Hoffman et al<sup>31</sup> matched patients with and without dementia based on age, sex, and physician contact. They compared the prevalence of painful chronic conditions (ie, cancer, arthritis, pain due to fracture, pain due to multimorbidity or dependency, headache, neuropathic pain, back pain, and unspecified pain) and their respective treatments. All conditions were equally prevalent, except for a higher prevalence in those with dementia for arthritis, fracture, neuropathic, back, and unspecified pain.<sup>31</sup> Another study by Plooij et al<sup>32</sup> conducted within Dutch nursing homes showed similar prevalence in those with and without dementia with regard to such pain conditions as rheumatoid arthritis, osteoporosis, hip fracture, other fractures, amputation, and cancer. In this study, 45% of patients with dementia who had at least one painful condition were not treated with an analgesic. In more current data, pain treatment prevalence has increased, likely because of more literature showing increased awareness with regard to pain prevalence in patients with dementia. Some even suggested overuse of certain medications, like acetaminophen, in these patients.<sup>33</sup> Therefore, conflicting information highlights how pain prevalence is not enough to determine the appropriateness of pain management.

## Pain Assessment

There are a variety of validated unidimensional and multidimensional pain assessment instruments used in practice today. Many of these tools are designed for use in

**TABLE: Nonverbal pain scales**

Nonverbal Pain Scale	Description
Doloplus-2	Observational 10-item questionnaire with 3 main categories: somatic, psychomotor, and psychosocial reactions Each item is scored 0-3 points, resulting in a score of 0-30 points. Generally a score of $\geq 5$ out of 30 is a positive sign of pain. <sup>35</sup> Available from: <a href="http://prc.coh.org/PainNOA/Doloplus%202_Tool.pdf">http://prc.coh.org/PainNOA/Doloplus%202_Tool.pdf</a> <sup>42</sup>
Algoplus	Similar to Doloplus but can be completed in less than 1 min If validated, the brevity of this scale would make it marketable to a variety of settings, including acute care. It is currently being validated in English. <sup>36</sup>
PAINAD	A unidimensional scale that has correlated well with pain severity based on 5 behavioral aspects: breathing, vocalization, facial expression, body language, and consolability Each aspect is rated on a 0- to 2-point scale, resulting in a score of 0-10. This scale was designed to mimic the numerical rating scale. <sup>37</sup> Available from: <a href="https://www.healthcare.uiowa.edu/igec/tools/pain/PAINAD.pdf">https://www.healthcare.uiowa.edu/igec/tools/pain/PAINAD.pdf</a> <sup>43</sup>
NOPPAIN	A worksheet that allows caregivers to document several observations during patient care: activity checklist, pain response, problem areas, and observed severity Within the activity checklist section, the caregiver can document yes or no depending on whether he or she believes pain was seen during activities such as positioning and activities of daily living <sup>38</sup> Available from: <a href="https://prc.coh.org/PainNOA/NOPPAIN_Tool.pdf">https://prc.coh.org/PainNOA/NOPPAIN_Tool.pdf</a> <sup>44</sup>

cognitively intact patients and are impractical for use in patients with dementia. It has been reported that the least effective scale is the visual analog scale, which consists of a 10-cm line that spans from “no pain” to “worst possible pain,” with the patient sliding an indicator to determine pain level. The best self-report scales include the verbal rating scale and the faces pain scale.<sup>34</sup> Numeric rating scales have been used with some success, depending on the level of cognitive impairment. These rating scales, however, are not useful in patients who are nonverbal. For those patients not able to complete a numeric rating scale, other tools have been developed for use in nonverbal or dementia patients, such as Doloplus-2, Algoplus, Pain Assessment in Advanced Dementia scale (PAINAD), and Non-communicative Patient’s Pain Assessment Instrument (NOPPAIN).<sup>35-38</sup> All of these tools have been validated in patients with dementia; however, these tools are not one size fits all. Therefore, it is up to the clinician preference regarding which scale to use. For a brief description of each, see the Table.

## Pain Management

There is no set guidance on how to treat pain specifically in patients with dementia. Analgesics are selected based on the most likely etiology of the pain (eg, nociceptive vs neuropathic pain), patient-related variables (eg, age, renal status, allergy history), and drug-related variables (eg, mechanism of action, adverse effect profile, pharmaceutical dosage formulation). Because most patients with dementia are elderly, it is important to follow pain

management guidelines published for older adults.<sup>39</sup> It should be noted that pain management should include nondrug strategies, such as massage, positioning, and physical therapy, in combination with pharmacologic agents to enhance efficacy.<sup>39</sup> The American Geriatrics Society guidelines recommend that providing analgesics on an “as needed” basis is not recommended in those with cognitive impairment because they may not be able to ask for the medication appropriately; therefore, medications should be scheduled, or provided before anticipated pain-inflicting events.<sup>39</sup> Pharmacologic American Geriatrics Society recommendations as applied to those with cognitive impairment are described below.<sup>39</sup>

## Nonopioids

Nonopioids (eg, acetaminophen and nonsteroidal anti-inflammatory drugs) are recommended as first-line agents in the management of pain. Acetaminophen is used often in the elderly because of its minimal side effects and drug interactions. Acetaminophen is not recommended in those at risk for liver toxicity or with heavy alcohol use. An adequate trial of acetaminophen is recommended before discontinuing, and an increase to 1000 mg per dose can be enough to provide relief as long as the total daily dose does not exceed 3 to 4 g in 24 hours. Dosing in excess of 4 g in 24 hours should be monitored carefully, especially in the setting of frequent use of combination products.<sup>39</sup>

Nonsteroidal anti-inflammatory drugs should be used with caution in the elderly, who are particularly susceptible to

adverse effects, such as gastrointestinal and renal toxicities. Approximately 20% of adverse drug-related admissions in the elderly are related to nonsteroidal anti-inflammatory drugs. If nonsteroidal anti-inflammatory drugs are indicated in a patient, then it is recommended to be paired with a proton pump inhibitor to provide gastric protection.<sup>39</sup>

## Opioids

Opioid analgesics may be appropriate for older adults experiencing moderate to severe pain that impairs functional ability or quality of life. However, opioids may worsen cognitive impairment and cause other adverse effects, such as constipation, nausea, and itching. All side effects should be anticipated and prevented if possible (eg, constipation). Patients with persistent pain where an opioid is appropriate therapy may benefit from using a long-acting formulation. Long-acting opioids should always be paired with a short-acting opioid for breakthrough pain or pain-provoking events, such as wound dressings or transfers. Methadone can also be used with caution by clinicians who have experience in the use.<sup>39</sup>

## Adjuvant Analgesics

Patients with suspected neuropathic pain are candidates for adjuvant analgesics. Adjuvant analgesics include gabapentinoids (eg, gabapentin, pregabalin), tricyclic antidepressants (eg, amitriptyline, nortriptyline, desipramine), antiepileptic drugs (eg, lamotrigine, carbamazepine), and serotonin-norepinephrine reuptake inhibitors (eg, duloxetine, venlafaxine). However, these agents should be used cautiously in older adults because of the increased risk of falls. Tricyclic antidepressants, although effective, should be avoided in the elderly because of their anticholinergic side effects. The lowest possible dose of these medications should be initiated and titrated slowly with extended intervals, knowing that the onset of efficacy may be delayed depending on the medication. Allow an adequate trial of a medication before discontinuation or switching to a different medication.<sup>39,40</sup>

## Clinical Implication for Practitioners

It is imperative that practitioners use a consistent approach to prevent, detect, and manage physical discomfort, and to recognize that pain may worsen behavioral disturbances. This differentiation is critically important to allow selection of the most appropriate pharmacotherapeutic regimens, specifically an analgesic regimen in lieu of an antipsychotic agent. Because of frequent tracers and penalties against nursing facilities with regard to antipsychotic use, it may be prudent for

facilities to assess pain and possibly treat with an analgesic trial before administering antipsychotics for agitation and aggressive-type behaviors.

Herr and colleagues<sup>41</sup> suggest a consistent process for the assessment and management of pain in patients unable to self-report pain, including infants/preverbal toddlers, and critically ill/unconscious, dementia, intellectual disability, and end-of-life patients. Specific considerations for dementia and end-of-life populations are as follows:

1. Obtain self-report of pain—this may be feasible in mild to moderate cognitive impairment but less likely with advanced dementia. Alternately, consider using a tool developed for nonverbal patients (see Table).
2. Search for potential causes of pain—as discussed above, patients with dementia suffer from painful conditions consistent with the general older adult population, such as musculoskeletal and neurologic disorders. Consider the patient's past medical history (eg, osteoarthritis, painful diabetic neuropathy, low back problems) and whether he or she is very likely to experience physical discomfort.
3. Observe patient behavior—this is an important element of all the pain assessment instruments used to assess nonverbal patients, as shown in the Table. This may include facial expressions, verbalizations or vocalizations, changes in activity patterns or mental status, and specific body movements.
4. Proxy reporting—pain and symptom management in advanced illness uses a team approach, and the management of pain in patients with dementia is no exception. Personal care providers, such as nursing assistants, can provide valuable information about potential pain. Family members who are familiar with how the patient manifests pain may also provide clues to possible pain management.
5. Attempt an analgesic trial—based on any available assessment information, often it is worth an empiric analgesic trial to assess patient response. For example, administering acetaminophen on a scheduled basis may be therapeutic. For moderate or severe pain, the patient may require an adjuvant analgesic (eg, antidepressant or anticonvulsant), or even an opioid. Use principles of safe prescribing by starting at lower opioid doses in older adults and increasing slowly, titrating to patient response.

In summary, patients with advanced dementia approaching the end of life have a high symptom burden. Pain is often underreported in this patient population because of their cognitive impairment. However, health care providers must anticipate this challenge and screen for and treat potential pain when possible.

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