Pain in Persons With Dementia: Complex, Common, and Challenging


Editor’s Note: This article is one in a series of “Case Reviews in Pain” to be presented by The Journal, designed to share scientific and clinical knowledge in a case review format. This report presents a discussion of pain management in a cognitively impaired older adult.

Case Study

An 82-year-old woman with moderate Alzheimer’s dementia presents to clinic with worsening agitation, aggression, and social withdrawal for the past 2 weeks. Her family reports that around the same time the patient injured her right ankle while transferring from the wheelchair to bed. Since that time, the patient reports moderate to severe pain continuously in the ankle with little relief from around-the-clock ibuprofen. Because of the change in her behaviors, the dose of her antipsychotic drug, quetiapine, was increased.

On review of systems, the patient complains of a poor appetite, difficulty sleeping, and not wanting to leave the house. Other pertinent history includes spinal stenosis and knee arthritis (treated with as needed acetaminophen), depression (treated with sertraline 100 mg daily), and blindness. She ambulates 2 to 3 steps with moderate assistance, mostly related to spinal stenosis and knee arthritis. The patient was diagnosed with Alzheimer’s dementia 4 years ago and is dependent in all of her instrumental activities of daily living; she is continent and can feed herself, but needs assistance with bathing, dressing, and transferring. Cognitively she is oriented to person, place, and year. She can recall 3 out of 3 words immediately, but 0 out of 3 words at 5 minutes. Her attention is intact.

Her vital signs are normal, but she lost 7 pounds since her last visit 1 month ago. The right ankle was swollen and painful with range of motion, but no skin break or erythema were noted. An x-ray of the ankle did not reveal a fracture. Ibuprofen was continued and liquid morphine 5 mg orally every 6 hours was added along with an appropriate bowel regimen. Within a few days, the patient’s pain decreased to a mild intensity, her appetite improved, she became more social, and the agitation resolved without increased confusion or sedation. This allowed the quetiapine dose to be decreased to the previously prescribed level.

Case provided by Joseph Shega, MD*
Linda Emanuel, MD, PhD†
*Division of Hematology-Oncology
†Director, Beuhler Center on Aging
Northwestern University
Feinberg School of Medicine
Chicago, IL

Manifestations of Pain in Cognitively Impaired Older Adults

Dementia is one of the leading causes of disability and diminished quality of life in older adults. The prevalence in the United States is expected to quadruple over the next 50 years such that 1 out of 45 Americans will be afflicted with the disease. Pain is also a leading contributor to disability in older adults and occurs in up to 80% of nursing home residents and 50% of community-dwelling elderly. Older adults often suffer from multiple coexisting illnesses such as musculoskeletal disorders and peripheral neuropathies that predispose to acute and chronic pain (Table 1). The patient in this case has several conditions which increase the risk of developing pain, including physical (spinal stenosis, arthritis), cognitive (dementia, depression), and sensory impairments (blindness). Moreover, she requires assistance with sev-
eral Activities of Daily Living, such as ambulation, which puts her at risk for falls and other injuries.

Despite the high prevalence of pain in this population, studies have shown that older patients receive inadequate pain control compared with younger individuals.\textsuperscript{4,30,36} Cognitively impaired patients may be at greatest risk of poor pain control due to underrecognition and undertreatment of pain. Alzheimer’s disease leads to pathological changes in the brain that afflict neurologic pathways associated with the affective component of pain. It is thought that persons with dementia may perceive a painful stimulus normally; however, the ability to remember, interpret, and respond to pain is altered.\textsuperscript{3} Instead, patients may manifest discomfort through challenging behaviors such as agitation, physical combativeness, verbal aggression, disruptive behavior, wandering, or social withdrawal. These changes can impede care, create distress in caregivers, and lead to physical restraints and psychotropic therapy.\textsuperscript{10} Identification of pain in these patients can be challenging as up to 90% of cognitively impaired individuals will develop behavioral and psychological symptoms from progression of the primary disease itself.\textsuperscript{6} Caregivers and clinicians may assume that worsening behaviors are due to the underlying disease process, rather than from a new source of discomfort.

The consequences of unrelieved pain can profoundly impact the quality of life of elderly patients (Table 2). Persistent pain leads to functional disturbances such as impaired ambulation, gait abnormalities, and decrease in recreational activities.\textsuperscript{34} Moreover, higher pain scores are correlated with increasing levels of physical disability and number of impairments in Activities of Daily Living.\textsuperscript{39} Undertreated pain can also lead to impaired psychosocial function in older adults. Persons with chronic nonmalignant pain perform lower on neuropsychological tests and have poorer mental flexibility than those without pain.\textsuperscript{22,38} Undertreated pain also results in significant mood disturbances such as depression, anxiety, and self-reported loss of enjoyment in life.\textsuperscript{18,26,34} In addition, increased pain intensity is independently associated with appetite impairment in community-dwelling older adults.\textsuperscript{3} Last, older adults with a history of chronic bodily pain are more likely to report significant sleep disturbances.\textsuperscript{16}

Physical and psychological impairments due to untreated pain can lead to learned helplessness, social isolation, and rising healthcare costs as dependency in activities of daily living require more help from caregivers and medical staff. Undertreated pain has also been associated with a decreased self-rated overall health assessment which has shown to be an independent predictor of death.\textsuperscript{32} The patient in this case exhibited many factors associated with untreated pain in persons with dementia including poor appetite, weight loss, difficulty sleeping, and social isolation. Once the painful condition was treated, her symptoms abated and she returned to her baseline.

The importance of performing thorough evaluations in cognitively impaired individuals with behavior changes cannot be underestimated. A patient demonstrating new or worsening agitation or social withdrawal may be responding to an unmet need such as hunger, loneliness, or fear. Behavioral changes may also be due to easily treatable physical discomforts such as constipation, urinary retention, improper positioning, or the exacerbation of an underlying painful condition.\textsuperscript{25} Because this patient has a history of depression and challenging behaviors, it was initially thought that an adjustment in the antipsychotic was indicated. However, treating challenging behaviors without searching for other etiologies first may lead to unnecessary use of restraints or psychotropics without correcting the root cause. The aggressive treatment of pain in this case demonstrates that a proactive approach to screening for, detecting and treating pain can positively impact the quality of life of older adults by effectively controlling symptoms with appropriate interventions.

Lisa Vargish, MD
Stacie K. Levine, MD
Section of Geriatric Medicine
Department of Medicine
University of Chicago
Chicago, IL

Challenges in Pain Assessment: How Do We Know When the Patient Cannot Tell Us?

Dementia patients experience pain but are often unable to interpret or communicate the sensation in a way that is recognizable. Typical presentations of pain such as

<table>
<thead>
<tr>
<th>Table 2. Consequences of Unrelieved Pain in Persons With Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PHYSICAL</strong></td>
</tr>
<tr>
<td>Gait impairment</td>
</tr>
<tr>
<td>Decreased appetite</td>
</tr>
<tr>
<td>Sleep disturbances</td>
</tr>
<tr>
<td>Agitation</td>
</tr>
<tr>
<td>Physical combativeness</td>
</tr>
<tr>
<td>Wandering</td>
</tr>
</tbody>
</table>

Table 1. Common Sources of Pain in Older Adults

- Degenerative joint disease
- Spinal stenosis
- Fractures
- Pressure ulcers
- Radiculopathy
- Urinary retention
- Constipation
- Vitamin D deficiency
- Polyneuropathy
- Coronary artery disease
- Post-stroke syndrome
- Improper positioning
- Fibromyalgia
- Cancer
- Contractures
- Postherpetic neuralgia
- Oral/dental
- Peripheral vascular disease
- Paget’s disease

The importance of performing thorough evaluations in cognitively impaired individuals with behavior changes cannot be underestimated. A patient demonstrating new or worsening agitation or social withdrawal may be responding to an unmet need such as hunger, loneliness, or fear. Behavioral changes may also be due to easily treatable physical discomforts such as constipation, urinary retention, improper positioning, or the exacerbation of an underlying painful condition. Because this patient has a history of depression and challenging behaviors, it was initially thought that an adjustment in the antipsychotic was indicated. However, treating challenging behaviors without searching for other etiologies first may lead to unnecessary use of restraints or psychotropics without correcting the root cause. The aggressive treatment of pain in this case demonstrates that a proactive approach to screening for, detecting and treating pain can positively impact the quality of life of older adults by effectively controlling symptoms with appropriate interventions.

Lisa Vargish, MD
Stacie K. Levine, MD
Section of Geriatric Medicine
Department of Medicine
University of Chicago
Chicago, IL

Challenges in Pain Assessment: How Do We Know When the Patient Cannot Tell Us?

Dementia patients experience pain but are often unable to interpret or communicate the sensation in a way that is recognizable. Typical presentations of pain such as

<table>
<thead>
<tr>
<th>Table 2. Consequences of Unrelieved Pain in Persons With Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PHYSICAL</strong></td>
</tr>
<tr>
<td>Gait impairment</td>
</tr>
<tr>
<td>Decreased appetite</td>
</tr>
<tr>
<td>Sleep disturbances</td>
</tr>
<tr>
<td>Agitation</td>
</tr>
<tr>
<td>Physical combativeness</td>
</tr>
<tr>
<td>Wandering</td>
</tr>
</tbody>
</table>
guarding, bracing or moaning may be replaced by expressions of fear, combativeness, agitation, and withdrawal. The complexities involved in the identification of pain contribute to underdiagnosis and undertreatment of pain in the cognitively impaired older patient population as has been highlighted in recent literature.

A comprehensive pain assessment serves several purposes: to identify the physiological etiology and comorbidities that contribute and shape the experience of pain, to determine the severity of pain and its impact on function and quality of life, to develop an intervention plan tailored to the individual's strengths and limitations, and to monitor and evaluate response to treatment. Clinical practice recommendations for pain assessment in patients with advanced dementia triangulate the search for physiological etiologies of pain with self-report, behavioral observation, proxy report, and response to analgesic trials.

This 82-year-old patient has chronic pain due to osteoarthritis with spinal stenosis limiting her overall mobility. Her pain experience is further worsened by depression, Alzheimer's disease, and blindness. Ideally, her primary caregivers or family members are familiar with her typical pain behaviors most likely elicited during movement-based activities such as dressing or transfers. The recent ankle injury has added severe acute pain and resultant anxiety to her controlled persistent pain. Despite cognitive impairment this patient is able to localize and rate her pain, assisting in the differentiation of acute and chronic pain and its severity.

Many mild to moderately cognitively impaired older patients are able to report pain in the here and now. Standardized pain scales are available to track pain intensity from diagnosis through treatment response with good reliability and validity. They are easily administered in the clinical setting but should be matched to the patient's cognitive and sensory limitations.

As cognitive impairment progresses to Mini-Mental Status Exam Scores <13 and patients become unable to respond even to prompting, clinicians and caregivers have to rely on observation of pain behaviors. State-of-the-science reviews of currently available behavioral assessment tools provide guidance in selection of a tool that is clinically usable and psychometrically sound. Assessment of pain behaviors in persons with dementia can be comprehensive taking note of changes in baseline behaviors or focused directly on behaviors as they are apparent during the examination. The American Geriatrics Society organized pain behaviors into six main categories including facial expressions (eg, fear with frowning, grimacing, closed or tightened eyes, or rapid blinking); vocalizations (eg, chanting, noisy breathing, calling out or asking for help); body movements (eg, rigid and tense, fidgeting, pacing or rocking); interpersonal interactions (eg, change in aggressive, disruptive or resistive behaviors or social withdrawal); changes in activity patterns (eg, eating and sleeping and physical movement routines); and metal status changes (eg, tearfulness and worsening confusion and irritability). Our patient demonstrated a worsening of agitation, aggression and social withdrawal, as well as weight loss. These are all triggers for a comprehensive pain assessment.

Corroboration with knowledgeable informants to complete items on multidimensional instruments that assess pain behaviors, mood, quality of life, coping resources, and social support is an important effort to validate presence of pain when obvious etiologies are not present. Caregivers with longstanding patient-relationships are in the best position to identify subtle changes in behavior but all must be educated in recognizing atypical behavioral presentations as potential pain indicators.

If potential pain behaviors persist after basic needs are ascertained, pathologic processes are addressed and nonpharmacologic interventions attempted, an analgesic trial is indicated. Here, this was done successfully only after the patient's antipsychotic medication dose was increased. When suspecting pain as the cause of a behavior change, it is advantageous to perform an analgesic trial first because it yields a quicker response in normalizing behavior, any adverse reaction to analgesics are generally less serious, and pain is actually relieved rather than masked by the sedative effects of the antipsychotic medication.

The Interdisciplinary Expert Consensus Statement on Assessment of Pain in Older Patients offers a comprehensive review of recommendations, tools, and procedures available to clinicians caring for both cognitively intact and impaired older patients. Adequate assessment is essential for clinical decision-making, implementation and ongoing evaluation of care. As more assessment tools become available and clinicians grow more skilled in detecting pain in the cognitively impaired there is hope that this fastest-growing segment of our older population will receive the pain relief it deserves but may not be able to ask for.

Heide Bursch, RN, MSN
Keela Herr, PhD, RN, FAAN, AGSF
College of Nursing
University of Iowa
Iowa City, IA

Weighing Treatment Options in Older Adults With Pain and Dementia

Pain is one of the most common medical symptoms of late life, and cognitive dysfunction is the most prevalent psychiatric disturbance. Managing comorbid pain and dementia may be challenging because of the potential overlap in their expression. Agitation, confusion, depressed mood, anorexia, apathy, and impaired sleep may
manifest in patients experiencing pain as well as those with dementia. Practitioners, therefore, must evaluate new symptoms or exacerbation of existing ones as potential manifestations of either or both disorders.

In addition to the potential for overlap in expression of pain and dementia, some of the medications used to treat pain, particularly opioid analgesics, may cause overlapping symptoms such as depression, delirium, and worsening of appetite and sleep. Before deciding to initiate these medications, therefore, their associated risks and benefits must be weighed carefully. Our patient was still in pain despite treatment with both ibuprofen and acetaminophen. She also appeared to be depressed despite treatment with sertraline, which was becoming socially isolated, losing weight, and was not sleeping—symptoms associated with poor quality of life and increased mortality rates. She was also agitated, resulting in increased use of quetiapine. Of note, while the use of such atypical antipsychotics are valuable for the management of agitated older adults with dementia, they are not without risk and have been associated with increased rates of adverse effects when used for the treatment of psychosis, aggression, or agitation in patients with Alzheimer’s disease.

In Table 3, we have outlined the parameters that should be considered when weighing the potential risks and benefits of prescribing opioids for older adults with dementia. Although pain and its attendant comorbidities may be reduced, opioids are associated with numerous potential side effects such as an increased risk of falls (less pertinent in our wheelchair-bound patient), sedation, delirium, depression, agitation, impaired sleep, and diminished appetite secondary to nausea and/or constipation. Clearly careful monitoring of the older adult in whom opioids are initiated is key; it is crucial that the practitioner assesses frequently for an appropriate stop date and terminates therapy with the opioid when it is no longer needed. For the opioid-naïve patient, it is also important to initiate treatment with a low-dose short acting agent (eg, liquid morphine, as in this case). Regarding the risk of increasing caregiver burden because of caregiver concerns about addiction, prevention is the key. That is, the health care provider should educate the patient and their caregiver about the meaning of addiction (ie, as compared with dependence) and the very unlikely nature of its occurrence.

Another important consideration in the patient with comorbid pain and dementia is the concomitant risk of depression. Our patient has prominent neurovegetative symptoms including weight loss, poor appetite and difficulty sleeping as well as agitation, aggression, and reclusiveness. While sleep, appetite, and mood are all affected by pain, these symptoms are all also consistent with a diagnosis of depression. Given her history of depression (which appears to be undertreated at sertraline 100 mg/d), undertreated pain, dementia, and blindness, she is at risk of developing a major depressive episode. Depression and pain are mutually exacerbating conditions. Although this patient lives in the community, for many older adults with dementia, especially those living in nursing homes, depression is undertreated and depression and pain are mutually exacerbating conditions. Although this patient lives in the community, for many older adults with dementia, especially those living in nursing homes, depression is undertreated and untreated.

To optimize the treatment of painful conditions in older adults with cognitive impairment, aggressive treatment of psychiatric comorbidity such as depression, anxiety, and sleep impairment will improve analgesia and minimize polypharmacy.

Optimal management of the older adult with comorbid pain and dementia requires both attention to detail as well as a balanced perspective of the big picture. A formulaic approach does not exist. There are no substitutes for careful comprehensive assessment, frequent reassessment, and ongoing communication with the patient and caregiver.

Jordan F. Karp, MD
Department of Psychiatry
Western Psychiatric Institute and Clinic
Pittsburgh, PA
Debra K. Weiner, MD
Department of Medicine, Department of Psychiatry and Department of Anesthesiology
University of Pittsburgh School of Medicine
Pittsburgh, PA

<table>
<thead>
<tr>
<th>PARAMETER</th>
<th>POTENTIAL BENEFIT</th>
<th>POTENTIAL RISK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Reduced severity</td>
<td>No change in severity but exposure to potential risks.</td>
</tr>
<tr>
<td>Polypharmacy</td>
<td>Reduced psychotropic polypharmacy</td>
<td>Perhaps no change in total number of drugs given; likely need addition of laxative.</td>
</tr>
<tr>
<td>Caregiver burden</td>
<td>Reduced</td>
<td>Increased if concern about dependence/addiction.</td>
</tr>
<tr>
<td>Mobility</td>
<td>Improved</td>
<td>Heightened risk of falls.</td>
</tr>
<tr>
<td>Cognitive function</td>
<td>Not known – perhaps reduced risk of delirium</td>
<td>May cause cognitive slowing as well as sedation; delirium is possible.</td>
</tr>
<tr>
<td>Psychological function</td>
<td>May improve with reduction in pain</td>
<td>May cause depression and/or agitation.</td>
</tr>
<tr>
<td>Sleep</td>
<td>Improved sleep may result if pain was interfering with sleep.</td>
<td>Impaired sleep architecture.</td>
</tr>
<tr>
<td>Appetite</td>
<td>Improved appetite may result if pain was interfering with appetite.</td>
<td>Nausea and/or constipation may cause impaired appetite.</td>
</tr>
</tbody>
</table>
References


37. Teno JM, Kabumoto G, Wettle T, Roy J, Mor V: Daily pain that was excruciating at some time in the previous week: prevalence, characteristics, and outcomes in nursing home residents. J Am Geriatr Soc 52:762-767, 2004

