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Assessment and management of pain in persons with dementia

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Introduction

World-wide 46.8 million individuals were living with dementia in 2015 representing \$818 billion in costs.¹ The number of people diagnosed with dementia is projected to reach 131.5 million by 2050.¹ Since the risk of developing a painful condition increases in the older adult population,¹ the numbers of people with both pain and dementia will increase,² presenting a significant public health and economic concern.¹ Pain in persons with dementia can be challenging to adequately measure,³ particularly as verbal and behavioral expressions of chronic pain may be diminished or absent despite the presence of pain.⁴ Although multiple tools exist to help assess pain in dementia,⁵ pain often remains inadequately treated even when the individual has been diagnosed with a painful condition.² Untreated pain in persons with dementia not only presents an ethical issue⁶ but also increases morbidity⁷ as well as financial, personal, and caregiver burdens.³

Pain in persons with dementia

The International Association for the Study of Pain (IASP) defines pain as an “unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.”⁸ Others have suggested pain is “a subjective feeling, with no known biologic markers. Proof of its presence and measurement of intensity rely entirely on self-reporting by the patient.”³ However, relying on self-report in people with dementia may be inappropriate as cognitive impairment worsens and the ability to speak is lost.⁹

For persons with severe dementia who have a limited ability to communicate, pain may be assessed by noting deviations from the patient’s normal behavior,^{3,4,10} which may result from alterations of neurobiology and neurophysiology.^{11,12} These alterations may also be what leads to impairment of communication verbally and expression of pain behaviorally.⁴ These alterations place persons with dementia at increased risk of unrecognized and undertreated, or untreated pain.⁴ This significantly increases the risk of suffering, inappropriate treatments,¹⁰ increased stress for caregivers,⁷ worsening of cognitive

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impairment,^{3,13} functional loss,¹³ depression,³ decreased immune function,^{3,13} exacerbation of co-morbidities,³ and compromised sleep.¹³ Combined these alterations and deficits contribute to an overall decreased quality of life for the individual with dementia^{4,10,13} ultimately resulting in the potential for higher costs to the health care system and increased emotional burden for caregivers and society in general.³

Neurophysiological^{12,14} and psychophysical¹⁵ studies have increased our understanding of pain processing in cognitively normal adults¹⁴ and those with dementia.^{4,13} Clinical and Neuroimaging studies offer preliminary evidence that people with dementia may still experience pain just as intensely, or even more intensely, than those without cognitive impairment,^{4,13} contradicting previous impressions about pain in dementia. When compared to healthy controls, people with dementia may recognize pain more slowly and be unable to communicate their pain, however, in contrast, the experience of intensity distress is increased¹⁶ while affective distress is similar or increased compared to healthy controls.¹⁶ Additionally, a recent study indicates there are possible sex differences in pain processing in dementia, with females likely feeling more intense pain than males while males feel more pain unpleasantness relative to females.¹⁴ Furthermore race may impact pain treatment with Black older adults receiving less opioids relative to White older adults.¹⁷

Pain assessment

While self-report of pain is the “gold standard” for assessment, assessing pain in severe dementia also relies on direct observation of behavior, and to a lesser extent physiological (e.g. pulse and blood pressure) changes. Physiologic changes as indicators of pain are less reliable due to multiple factors that may alter the indicator such as medications (blood pressure meds, pain medications, sedatives, beta blockers, etc.). Also of note is that vital signs may not be a reliable indicator during chronic pain because many indicators have habituated during the transition to chronic pain.

There are at least 28 observational behavioral tools used for pain assessment in persons with dementia. However, due to limited testing, there is no consensus on which ones are best for clinical practice. Two examples of tools suggested more frequently include the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) scale,¹⁸ and Pain Assessment In Advanced Dementia (PAINAD) scale.¹⁹ The PACSLAC, one of the more comprehensive and complex scales, covers items such as facial expression, activity and body movement, social/personality/mood, physiological changes, eating and sleeping changes, and vocal behaviors. Most of the other 27 scales involve items from these categories in a pared-down form. Based on our brief review, we suggest that the PAINAD is more practical for clinical use, particularly in busy settings.

The PAINAD¹⁴ consists of five items of breathing, facial expressions, vocalizations, body language, and consolability. Scoring for each item is from 0–3, and then totaled, with larger scores indicating more pain. The scale requires some training and a brief patient observation (around 5 minutes) before it can be competently used. See^{14,19} for a copy of the tool and psychometric properties of the PAINAD. The PAINAD received the highest score for a

variety of markers, including psychometrics, from a comprehensive review (see <http://prc.coh.org/PAIN-NOA.htm> for this review of the PAINAD as well as 16 other tools).

In addition to observational pain scales, the patient's chart should be reviewed for diagnoses that may cause pain. Preemptive treatment may be indicated. Likewise, discussing causes of pain, known expressions of pain (including behavioral changes), as well as preferred and failed treatments with the patient's caregiver may yield helpful information.

Pain treatment

In addition to controlling pain and promoting comfort, pain management goals for persons with dementia should include improving function, promoting quality of life, and preventing further injury.²⁰ Inherent in some pain therapies are risks ranging from sedation to exacerbation of underlying health conditions, therefore, prior to initiating treatment, clinicians should conduct thorough discussions with patient and/or proxy to determine goals and priorities of care.²⁰ Achieving adequate pain control in persons with dementia should be an iterative process of treatment trials followed by reassessment using the same measurement tool and treatment plan adjustment as needed until goals are met.

Nonpharmacological

Nonpharmacological pain treatment in persons with dementia may include complementary and alternative medicine therapies. One superior aspect of these therapies is that most are noninvasive and some can be learned with minimal training (e.g., massage, use of essential oils, application of heat or cold).²¹ Clinicians can advise engagement with nonpharmacological therapies according to the patient's ability to participate and suspected source or type of pain. Strategies requiring more invasive and extensive education or training include physical therapy, acupuncture, reflexology, and chiropractic care.²¹ Additionally, simple interventions such as relaxation, distraction, environmental modifications, and the presence of a loved one have also been useful in reducing pain.²⁰ Exercise may be helpful, particularly in earlier stages of disease, and may benefit both comfort and function.^{20,22} In sum, nonpharmacologic therapies and interventions hold great promise for providing relief from pain and suffering without ingesting potentially dangerous medications or receiving complex injection protocols. When possible, and if successful, we recommend nonpharmacologic options when pain is diagnosed in persons with dementia. Ultimately screening for level of dementia severity using a simple tool such as the Mini Mental State Exam²³ provides a simple proxy measure for dementia severity and thus the likelihood of which interventions will be most effective.

Pharmacological

Originally developed for use in persons with malignancies, the World Health Organization (WHO) analgesic treatment ladder²⁴ is useful in managing painful conditions in persons with dementia. The WHO analgesic ladder advises beginning with non-opioid analgesics, with or without adjuvant therapies; if pain persists, opioid options may be pursued in place of, or in addition to, non-opioid therapies.²⁴ Throughout treatment trials, clinicians should

be mindful of pharmacokinetic and pharmacodynamic changes associated with aging, starting with lower doses and titrating slowly upward as needed (“start low, go slow”).^{20,25}

Acetaminophen is a common first-line treatment for pain and can be a useful option for older adults.²⁶ It acts centrally to prevent the formation of prostaglandins, preventing inflammation, fever, and pain.²⁷ Acetaminophen has relatively few side effects, and its chief safety concern is hepatotoxicity related to unintentional overdose.²² Patients should not exceed a total daily dose of 4,000 mg of acetaminophen, and it’s important to consider all potential sources of acetaminophen, including any contained in opioid preparations.²⁸

Non-steroidal anti-inflammatory drugs (NSAIDs) are another non-opioid class that is commonly prescribed for pain, but in contrast to acetaminophen, NSAIDs have potentially serious side effects that are particularly relevant to older adults.²⁵ For this reason, the 2015 Beers Criteria suggests that this class be used at the lowest dose to ameliorate symptoms while keeping duration of time exposed to a minimum.²⁵ Non-steroidal anti-inflammatory agents have potential adverse effects associated with both cyclooxygenase (COX)-1 and COX-2 activity. Agents such as naproxen that are COX-1 dominant have higher risk for gastrointestinal injury, while agents such as ibuprofen, meloxicam, and celecoxib that are COX-2 dominant or selective have higher risk for cardiovascular and renal injury.²² Clinicians may match relative risk profiles when considering which NSAID to advise for a specific patient, taking into account their past medical history and relevant gastric, cardiovascular, and renal comorbidities.²² All NSAIDs are contraindicated in patients with a history of heart failure.²⁵

Adjuvant strategies such as tricyclic antidepressants (TCAs), serotonin norepinephrine reuptake inhibitors (SNRIs), and anticonvulsants may be trialed, particularly for patients with suspected neuropathic pain or who have a comorbid mood disorder. These classes should be avoided or used with caution in patients with a history of falls.²⁵ Skeletal muscle relaxants should be avoided in persons with dementia due to risk of falls and anticholinergic burden.^{20,25} Topical agents such as lidocaine patches, capsaicin cream, and diclofenac gel may be useful for persons with localized pain, and these strategies are generally non-toxic for older adults.

Finally, the WHO guidelines suggests that when pain persists despite use of non-opioid agents, an opioid trial is appropriate.²⁴ Common adverse effects of opioids in older adults include constipation, mental status change, and nausea, therefore clinicians should monitor patients frequently for side effects.^{20,25} However, potential adverse effects can often be avoided by starting with low doses and titrating slowly, and concern for potential adverse effects should not prevent clinicians from trialing opioids in patients who have refractory pain.²⁰ Throughout therapy, clinicians should discuss care goals with patients and/or families; for instance, some patients and/or families may prefer sedation to refractory pain, whereas others may find sedation to be bothersome. Concern for opioid misuse and other narcotic diversion²⁹ in this population is generally low, but clinicians should be mindful of safety concerns such as falls and increased confusion.²⁰ Consideration of tolerance/dependence may be considered alongside life expectancy. Bowel function should be followed closely with implementation of laxatives as needed.²⁰

Conclusion

As the population continues to age and the numbers of older adults with both pain and dementia increase, the importance of nurse practitioners providing quality care for these individuals is clear.³⁰ Remembering that persons with dementia do feel pain despite cognitive impairment and potentially in the absence of behavioral expressions of pain is crucial for proper treatment. Using a combination of observational pain scales, detailed pain history, and thorough patient/proxy and provider communication will increase the likelihood of recognizing pain and help guide appropriate non-pharmacologic and pharmacologic therapies to improve pain management in persons with dementia.

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