CE

Advanced Dementia Care

Demystifying Behaviors, Addressing Pain, and Maximizing Comfort

Research and Practice: Partners in Care

Maribeth Gallagher, MS, RN, PMHNP-BC ❍ Carol O. Long, PhD, RN, FPCN

The graying of America will lead to an unprecedented and overwhelming number of people with dementia. As the numbers of persons with advanced dementia continue to rise, hospice and palliative care clinicians struggle to offer the same excellent care afforded patients with more common hospice diagnoses. Challenging behaviors occur in up to 90% of persons with dementia and are distressing for patients and caregivers alike. Nursing theories and emerging evidence-based practices offer guidance to help clinicians recognize, interpret, and respond to the palliative care needs of persons with advanced dementia. Caregivers must explore the possible causes for behaviors by considering a wide array of potentially unmet physical, psychological, emotional, spiritual, and environmental needs in the person with advanced dementia. Pain is a common cause for challenging behaviors in these individuals, yet it frequently goes unrecognized and/or undertreated. This article uses a case study to illustrate a common challenge faced by clinicians serving patients with advanced dementia and provides a detailed discussion on current best practices to improve palliative care for persons with advanced dementia and their caregivers.

KEY WORDS

advanced dementia, behaviors, hospice, pain, palliative care

Mrs T. is an 83-year-old retired grade-school teacher with a history of Alzheimer disease (AD), hypertension, congestive heart failure, and osteoarthritis. She resides in an assisted-living home (ALH) and receives hospice services for advanced dementia. Mrs T. is unable to dress, bathe, or ambulate without maximum assistance and is incontinent of bowel and bladder. She has a Mini-Mental State Examination score of 4/30, indicating global cognitive impairment associated with late-stage dementia. Her severely impaired communication skills limit her verbal exchanges to a few stereotypical phrases such as "OK" and "thank you." Mrs T. occasionally demonstrates swallowing difficulties when being fed her meals and had pneumonia 4 months ago. She was treated with antibiotics as stipulated by her advanced directives and recovered.

The direct caregivers, who are unlicensed staff at the ALH, report that Mrs T. is awaking in the middle of the night and yelling loudly, which disturbs the other residents. They state she will not return to sleep when caregivers offer comfort and reassurance, but eventually dozes off and on until dawn. Additionally, Mrs T. has recently started to exhibit increasingly agitated and resistive behaviors when receiving personal care. Mrs T. repeatedly cries "stop" and "help" loudly while striking out with clenched fists as caregivers try to reposition or transfer her during personal care tasks. She demonstrates facial grimacing and tension throughout her entire body during these episodes. Caregivers report that their attempts to distract Mrs T. with conversations about her earlier years as a teacher prove unsuccessful, and the behaviors continue until the caregiving tasks are completed. The hospice RN case manager receives a call from the ALH's owner describing Mrs T.'s "combative and disruptive behaviors" and states that the RN must do something to reduce the behaviors or Mrs T. may need to go to a different facility. The ALH's owner suggests haloperidol or quetiapine as she has seen it effectively calm other residents' behaviors and help them sleep through the night. The RN explains that instead of choosing a sedating medication to make the behaviors cease, evidence-based practices suggest that Mrs T.'s behaviors may signal an underlying problem that must be explored and remedied. The RN assures the ALH owner that she will start immediately to investigate the changes in behaviors, address the cause(s) with the hospice medical director, and communicate her findings and planned interventions.

Maribeth Gallagher, MS, RN, PMHNP-BC, Dementia Program Director, Hospice of the Valley, Phoenix, AZ.

Carol O. Long, PhD, RN, FPCN, Geriatric Consultant and Codirector, Palliative Care for Advanced Dementia, Beatitudes Campus, Phoenix, AZ.

Address correspondence to Maribeth Gallagher, MS, RN, PMHNP-BC, Hospice of the Valley, 1510 E. Flower St, Phoenix, AZ 85014 (mgallagher@hov.org).

No funding was received for this study.

The authors declare no conflict of interest.

DOI: 10.1097/NJH.0b013e318201975d

The aforementioned scenario may sound increasingly familiar to nurses serving the needs of persons with advanced dementia. Challenging behaviors are not only distressing for patients but for caregivers as well. The purpose of this article is to share evidence-based approaches to help caregivers systematically investigate the underlying causes for challenging behaviors and to guide effective responses for maximizing comfort in persons with advanced dementia. Common triggers such as delirium and environmental factors will be presented, but the emphasis of the discussion will focus on recognizing, interpreting, and responding to pain in an effort to improve palliative care for persons with advanced dementia and their caregivers.

DEMENTIA ON THE RISE—IMPLICATIONS FOR HOSPICE

The graying of America will lead to an unprecedented and overwhelming number of people with dementia. Every 70 seconds, someone in the United States develops a form of dementia known as AD.[1] Adults 85 years or older are the fastest-growing segment of many populations worldwide, and approximately one of every two of these adults have AD.[2] Moreover, it is estimated that one of eight people 65 years or older has AD, and as of January 1, 2011, as many as 10,000 baby boomers will turn 65 years old every day.[1,3] Alzheimer disease is one of several forms of dementia for which there is currently no cure or method to effectively halt or reverse the progressive neurodegenerative damage that results in severe loss of cognition, function, and eventually death. Currently, there are more than 5.3 million Americans with AD, and another 2 million with non-Alzheimer dementia.[1]

As dementia continues to emerge as a leading cause of death in older Americans, the burgeoning need for excellent palliative dementia care continues to grow. To date, studies suggest that patients with dementia receive suboptimal end-of-life care, experiencing distressing symptoms and burdensome interventions.[4-8] Hospice and palliative care teams are challenged with providing the same quality services for persons with dementia and their families, as they expertly provide for patients and families with more common hospice diagnoses.[8] The most important goal of care commonly identified by an overwhelming majority of healthcare proxies for patients with advanced dementia in nursing homes is comfort.[6] Although established goals of care should guide treatment choices for all patients, it is frequently difficult for caregivers to confidently anticipate and fulfill the needs of persons who are unable to verbally convey their experiences because of impaired cognition and communication. Caregivers must blend their clinical expertise and knowledge of the best available empirical evidence, with their understanding of patients' preferences and values, to achieve improved outcomes.[9] By integrating evidence-based practices into their decision-making processes, clinicians can more confidently and consistently offer palliative dementia care that reflects the very best of both the art and science of nursing.

THEORETICAL FRAMEWORKS

Nursing theories have been constructed to demystify dementia-related behaviors and provide guidance for practitioners to effectively anticipate and respond to the needs of persons with dementia. Two of the theories offering interpretation of the behaviors that typically accompany the progression of dementia are presented here. Hall and Buckwalter[10] conceptualized the Progressively Lowered Stress Threshold model, proposing that progressive neurodegenerative changes in dementia lead to decreased abilities in those affected by the disease to effectively decipher and respond to both internal and external stimuli. Therefore, persons experience increasing difficulty in their abilities to process, adjust to, tolerate, or cope with stimuli as they did in the past. As such, they begin to experience more stressful reactions as evidenced by increased anxiety and dysfunctional behaviors. In other words, as dementia progresses, the person becomes increasingly vulnerable to stressors, which may trigger discomfort and negative behaviors. Six types of triggers are identified: fatigue, change, repose to perception of losses, inappropriate stimulus levels, excessive demands, and physical stressors such as pain, infection, and medications causing delirium. The Progressively Lowered Stress Threshold model highlights that behaviors have meaning. If disturbing behaviors are a departure from a person's normative behaviors, they serve as an effective means of communication for the person with dementia. This compels caregivers to search for and address the underlying causes.[10]

Another explanation focuses on these behaviors as manifestation or communication of unmet need.[11] Expanding on this concept, the Consequences of Need-driven, Dementia-Compromised Behavior (C-NDB) theory suggests that the person with dementia is unable to make his/her needs known, and the caregiver is unable to determine what the behaviors mean.[12] As such, the nurse, in this example, does not know the cause or magnitude of Mrs T.'s needs. When needs are unmet, behaviors emerge, creating a "cascading" effect for the person with dementia whereby background and proximal factors affect the person's primary needs. When these needs are not met, primary need-driven dementia-compromised behaviors emerge. Unmet primary needs may lead to secondary needs, and secondary need-driven dementia compromised behaviors. Thus, the cycle continues until the needs are assessed and addressed.

Correspondingly, the Serial Trial Intervention capitalizes on the Consequences of Need-driven, Dementia-Compromised Behavior theoretical model and Assessment of Discomfort in Dementia Protocol, in which serial assessments and sequential trials of treatments or interventions identify and treat unmet needs that may be the cause of dementia-related behaviors.[13,14] It is important for caregivers to frequently anticipate even the simplest of unmet needs in the persons with dementia, such as thirst, hunger, feeling hot or cold, and fatigue. Those most at risk for experiencing unmet needs are individuals, such as those with advanced dementia, who can no longer identify or verbally tell caregivers the source of their discomfort or pain. Thus, caregivers must anticipate the person's physical, spiritual, and/or affective needs and provide nonpharmacological and pharmacological interventions with continual assessment and reevaluation of the person's response to treatment.

CHALLENGING BEHAVIORS—THE SEARCH FOR UNDERLYING CAUSES

Although there is wide variation in the literature, episodes of behavioral disturbances are estimated to occur in up to 90% of persons with dementia and may have multiple underlying causes.[15-17] Caregivers must explore the possible causes for behaviors by considering a broad array of potentially unmet physical, psychological, emotional, spiritual, and environmental needs in the person with advanced dementia.[8,18] Although identification and discussion of the numerous potential underlying causes for dementia-related behaviors are too extensive to cover in one article, considerations for the commonly occurring factors of delirium, environmental stimuli, and pain are explored here.

Considerations for Delirium

The diagnosis of delirium in persons with dementia is commonly missed by clinicians because the presentations are mistakenly perceived as being part of the chronic day-to-day confusion of dementia or attributed to behaviors labeled as sundowning.[19,20] Delirium occurs in up to 60% of nursing home residents and up to 83% of patients at end of life.[21,22] The occurrence of delirium superimposed on dementia is estimated to range between 22% and 89% in older adult populations.[23] Patients with dementia and multiple illnesses are at highest risks for developing delirium, so caregivers must remain vigilant and suspect delirium whenever there is a new onset or increase in the frequency or severity of cognitive, functional, or behavioral changes that erupt over hours to days.[20,24,25] Acute changes from baseline in mental status (with possible fluctuations) and inattention, along with disorganized thinking and/or altered levels of consciousness, should signal further assessments for delirium.[20,23-25] Early recognition is imperative to provide interventions that may reverse the underlying cause(s) and improve patient outcomes or simply maintain patients' safety and comfort.[19,25] Although delirium may have numerous causes, caregivers should begin by investigating common causes such as infections and other intercurrent illnesses, medications, dehydration, pain, altered laboratory values, sensory alterations due to lack of eyeglasses or hearing aids, and environmental conditions such as sleep deprivation.[19,20] Based on the patient's advance directives, underlying causes for delirium, such as infection, may or may not be treated with antibiotics. Regardless of the healthcare decision options chosen, caregivers must ensure that methods are used to keep the patient comfortable by utilizing pharmacological and/or nonpharmacological methods.

Delirium may present with one or more motoric subtypes such as hyperactive, hypoactive, or mixed.[19] Patients who demonstrate a recent onset of behaviors that are obvious departures from baseline behaviors, such as increased agitation, hypervigilance, restlessness, wandering, and falling, warrant investigation for a hyperactive delirium. In the case study, Mrs T.'s agitated and distressing behaviors, along with changes in her typical sleep patterns, are described as "recently" occurring events. The RN case manager recognizes that these behaviors are not part of Mrs T.'s normative behaviors and begins to suspect possible underlying causes of a delirium. The RN knows it is important to suspect delirium and search for its causes, as empiric evidence confirms that inappropriately medicating the patient to simply stop the behaviors leads to poorer patient outcomes.[25]

Considerations for Environmental Stimuli

Although the focus of this article is on pain, it is essential for caregivers to keep in mind that environmental factors and caregiver approaches may trigger or contribute to discomfort in the person with dementia.[10,26] Environmental modification is typically required to create surroundings that capitalize on comfort and minimize distress through the input of all of the five functioning senses. Caregivers are urged to try and sense the environment from the cognitively impaired patient's perspective. Make sure that eyeglasses and hearing aids are used as tolerated to assist persons to more accurately interpret their surroundings and facilitate communication with others. How might you be perceived by the person? Is your presence conveying respect and safety? Are you making direct eye contact at or below the level of the patient's eyes? What does your tone of voice and body language convey? Are you adjusting the pace and content of your communication and caregiving tasks to accommodate for the slower processing and language impairment that occurs with dementia to maximize the patient's comprehension of what you are doing and why?[27-29]

Have you ensured that the physical environment is as comfortable as possible? Is the room too cold or hot, causing discomfort for the patient? Do the sounds from the radio or television impart messages that might cause the patient to feel angry or afraid? How might the sounds of war coming from the news station impact the emotions of a veteran of the armed services who is now confused and uncertain of his/her surroundings? Both overstimulation and understimulation may contribute to agitation, so it is important to determine what is best for the individual patient and customize the surroundings to optimize well-being.[10,30] Finally, it is important for caregivers to know the person with dementia so they can use this important and extremely useful information to tailor person-centered care interventions that honor patients' lifelong pleasurable preferences to maximize caregiving strategies toward ensuring comfort and enhancing quality of life. Caregivers can utilize information from forms such as the *About Me*[27] to modify the environment and caregiving tasks so that every interaction with the patient affirms their personhood and enhances quality of life.[27,31]

Considerations for Pain

In addition to assessing for environmental and unmet needs, it is important to consider pain in a differential diagnosis when exploring the etiology of unexplained behaviors in persons with advanced dementia. Pain is commonly underrecognized and undertreated in older adults with dementia and is a significant underlying factor for challenging behaviors.[26,32,33] Changes in memory, insight, judgment, and language in persons with dementia serve as barriers to effectively recognize, recall, and communicate pain to caregivers.[26,34,35] Persons with advanced dementia have very limited, if any, ability to self-report pain. As a result, pain is poorly managed in cognitively impaired elders with painful comorbidities and may lead to negative sequelae such as sleep disturbances, functional decline, poor oral intake, physical deterioration, social isolation, dysphoria, and further impaired cognition.[26,32]

There is a growing body of empiric literature emphasizing the importance of recognizing and treating pain in the cognitively impaired older adult based on five overall assumptions: (1) pain is underrecognized and undertreated in older adults, particularly those with dementia; (2) pain is underreported by cognitively impaired persons; (3) pain may contribute to challenging behaviors; (4) dementia caregivers need to consistently use one of the pain tools designed to recognize pain in persons with moderate to advanced dementia; and (5) trials of routinely administered pain medications are warranted in older adults with dementia who demonstrate behaviors not attributable to other causes.[5-8,13,14,26,29,32,34-37]

Dispelling the Myths

It is essential to dispel common misconceptions associated with pain in older cognitively impaired adults. The parts of the brain that interpret pain, called the somatosensory cortex, remain intact in persons with AD.[38] Although the neuropathological changes that occur with dementia may impair patients from accurately recognizing, interpreting, and communicating their discomfort as "pain," they still experience pain but may exhibit atypical responses such as yelling, hitting, and resisting care.[32]

Despite that pain may be processed and perceived differently in persons with dementia, there is scientific evidence suggesting that persons with dementia sense even low levels of pain.[39] Another study indicates that those with dementia and in acute pain may not experience vital sign changes compared with those who are cognitively intact.[40] Additional research has shown that persons with dementia may require more analgesic to produce adequate pain relief.[41] Often, professional staff may not ask the person directly about their pain, assuming that the person cannot self-report, when, in fact, there may be moments when the person is able to report the presence and possibly the intensity of pain if he/she is provided enough time to respond.[42] In the end, persons with dementia may not receive prompt assessment and adequate treatment for their pain. This is exacerbated by the common misperception that a sleeping or sedated patient indicates a comfortable patient, when, in fact, this may be an erroneous assumption.[43]

Collateral Information and Empiric Treatment of Pain

In addition to inquiring about pain from the patient, it is imperative that clinicians review the patient's medical history and perform a physical examination to search for old and new causes of pain. Older adults frequently have multiple chronic conditions that may cause pain, such as arthritis, neuropathies, peripheral vascular disease, and degenerative conditions of the spine.[8,26] Scheduled medications are recommended rather than on as 'as needed" basis, particularly for cognitively impaired patients who may be unable to identify pain and communicate the need for medication.[32] More effective pain management is attained by administering around-the-clock pain medications to maintain a steady state of analgesic blood concentration.[26] It is also important to intentionally administer pain medications prior to anticipated activities so they may effectively prevent painful episodes and maximize comfort.[26]

Older adults with chronic, persistent pain may demonstrate sensitivity to analgesic medications, so it is always advised to start low on the dosage, and titrate up slowly, watching closely for any negative reactions.[26] It is also important to recognize that older adults comprise a wide heterogeneous group, and decisions regarding appropriate medications and dosages must be made on an individual basis with frequent reassessments to ensure effective pain relief and monitor for negative effects.[26] Remember to trial nonpharmacological methods, such as sensory and spiritual experiences, customized to the preferences of the individual, in addition to medications to enhance efforts for comfort.[26] Soothing music, a gentle hand or foot massage, prayer, or a sweet snack are just a few ways to provide comfort and pleasurable distraction through the senses.[27,44-48] Document methods that work in the patient's medical record, and communicate them to team members across all shifts.

Evidence-Based Approaches for Assessing and Addressing Pain

Evidence-based findings and clinical interpretation guide practice. Adopting the *Hierarchy of Pain Assessment Techniques* is recommended as a set of practice guidelines for assessing and addressing pain in persons who are nonverbal or cognitively impaired.[34,49,50] In addition, securing a reliable and valid pain rating scale is necessary. The general guidelines and recommendations that specify pain assessment and management in persons with dementia, such as for Mrs T., are as follows:

1. The person's self-report of pain is the most accurate indicator of the existence and intensity of pain. However, persons with advanced dementia may not able to report their pain. Be sure to ask if they are having pain right now. However, no complaint of pain does not mean the person does not have pain. If self-report cannot be solicited, document why. In this case scenario, Mrs T. is unable to provide self-report on her discomfort because of her advanced stage of dementia.
2. Identify the causes of pain and discomfort. Review the person's history and medical record. Look for established diagnoses of painful conditions or any new source of pain. Conduct a physical examination and focus on any sites that may be producing pain. Note pain on movement and activities. For Mrs T., her documented history of extensive osteoarthritis, combined with reports that her disruptive behaviors began when caregivers provided range of motion with personal care, shed clues that pain is at least one component contributing to her distress.
3. List and identify behaviors that are suggestive of pain. Examine when these behaviors occur. Knowing the person is key during this assessment. Note any specific changes from the norm. For example, if the person is normally happy during activities and now becomes sullen and cries, this would be a change in behaviors. Be astute to obvious signs of discomfort, such as facial grimacing and rubbing or bracing a body part. Less obvious cues may be decreased appetite, restlessness, calling out, and withdrawal during touch, movement, or repositioning, to name a few. Use a reliable and valid behavioral pain assessment scale. In this case, Mrs T. exhibits grimacing, crying out, and clenched fists with movement.
4. Secure a report from the caregiver, family, or others caring for this person. List all behaviors that suggest pain, the time of day, and what makes the behavior worse or better (see illustration by RN's assessment in the follow-up to case study). Caregivers should trial nonpharmacological methods to determine if they serve to even partially offer comfort, distraction, or consolation. The caregivers in the case scenario tried to talk about Mrs T.'s accomplishments as a school teacher because it is her favorite topic and typically evokes a positive response.
5. Identify the source of discomfort or pain. Remediate any acute conditions or delirium in accordance with the patient's advanced directives and goals of care (eg, urinary tract infection, pneumonia, fracture related to a fall). If the source of pain is related to a poor seating arrangement for the person, reposition the person. Conduct a serial trial intervention with an appropriate analgesic to address the estimated intensity of pain. Administer pain medication and determine the effectiveness. Determine if the medication is needed around-the-clock (eg, management of arthritis), before activities (eg, dressing, bathing), or before a painful procedure (eg, pressure ulcer dressing change). Engage the entire caregiving team to note the person's response to the medication and whether behaviors are mitigated or disappear or if they escalate, suggesting the need for additional or different pain medication. If antipsychotic medications are used to address disturbing psychotic signs and symptoms, remember they are not intended to treat pain. This is an important issue to stress because antipsychotic medications continue to be overused for the treatment of behaviors in dementia without first investigating and addressing possible underlying causes of behaviors.[51,52] Antipsychotic medications used for the treatment of agitation in dementia pose serious risks for morbidity and mortality including parkinsonism, excessive sedation, a threefold increase in stroke, and twice the risk of mortality and therefore should be considered only when necessary.[51,52]

As the hierarchy assists the clinician in a stepwise approach to address pain, there is the need to utilize a reliable and valid pain observation instrument, if the person cannot self-report, such as Mrs T. in this case study. There is a wide range of pain rating scales for nonverbal adults with dementia available for use across healthcare settings.[50] One tool that has been tested in the nursing home and is widely used in long-term-care and hospice settings is the Pain Assessment in Advanced Dementia or PAINAD.[53] The PAINAD is used in this case study and became part of the assessment process for Mrs T. when she could no longer self-report or use other numeric or verbal rating scales. The PAINAD is an observer-based pain-behavior assessment tool that identifies the presence of five categories of behaviors: breathing, negative vocalizations, facial expression, body languages, and consolability. Items are scored on a scale of 0 to 2, and a summary score ranges from 0 to 10. The tool possesses reliability and validity, is easy to use for licensed and unlicensed staff, and has demonstrated sensitivity to change.[43] Some hospices train all members of the interdisciplinary hospice team and volunteers to use the PAINAD so that every interaction with the patient provides an opportunity to observe for comfort and use a consistent communication method to alert the RN case manager when signs of discomfort are observed.

Follow-up to Case Scenario: Assessment, Intervention, and Evaluation

Mrs T.'s RN requests that the direct caregivers provide more exact details related to Mrs T.'s behavioral episodes. The RN asks deliberate questions to clearly identify any clues through temporal patterns influencing when the behaviors begin and end (eg, behaviors initiate with repositioning during personal care and cease when caregivers complete the tasks). She documents all of Mrs T.'s reported behaviors in detail to obtain a comprehensive perspective of the exact characteristics of the episodes, rather than using the word "agitation" as a vague descriptor. She notes that Mrs T. demonstrates facial grimacing, yells "stop" and "help," strikes out at caregivers with clenched fists, and tenses her body. Using the PAINAD tool, the RN documents Mrs T.'s score as 8/10 and realizes Mrs T. may possibly be experiencing severe pain with range of motion. The RN then inquires about any exacerbating or remitting factors (eg, behaviors escalate with increased range of motion and cease quickly after movement stops), particularly focusing on any potential methods to console or distract the patient. She learns that caregivers attempt to distract the patient using her favorite topic about earlier accomplishments as a teacher, but Mrs T. is not distractible. The RN checks to ensure that caregivers have assessed the patient for unmet needs such as hunger and thirst. She inquires if they are keeping the patient warm, providing privacy and covering the patient's exposed body parts during care, and moving slowly and respectfully through the process of personal caregiving while informing Mrs T. of what is being done, to determine if the caregivers' personal care methods are unintentionally contributing to Mrs T.'s discomfort.

As part of her thorough assessment, and based on her knowledge that patients with dementia are at high risk for delirium, the RN rules out any preliminary suspicions of delirium by examining possible causes such as signs and symptoms of infections and recent changes in medications. She also determines, through questioning caregivers, that Mrs T. is not demonstrating any changes in mental status or attention and shows no evidence of hallucinations or delusions. She reviews the patient's vital signs and performs a physical examination to identify possible underlying causes of discomfort such as skin breakdown, constipation, and urinary retention. Lastly, the RN assesses the surrounding environment for any sensory stimuli that may be misperceived or overstimulate the patient and contribute to her discomfort such as drafts from an air-conditioning vent or window, glare, or sounds from the television or radio.

Upon reviewing the patient's history, the RN notes Mrs T. has a long history of extensive osteoarthritis, which lends evidence for the PAINAD score of 8/10 with movement. Although Mrs T.'s medication list reveals an order for acetaminophen as needed, the documentation demonstrates that Mrs T. has not received any medications for pain. The RN discusses her findings with the hospice medical director and receives orders for analgesic medication targeting pain. She will closely monitor Mrs T.'s response and report back to the medical director for any further changes in medications. Mrs T. will receive acetaminophen 1000 mg every 6 hours to trial around the clock analgesia for her osteoarthritis.[26,34] She was also prescribed a fast-acting low-dose opioid as a PRN analgesic. The nurse will educate the caregivers to schedule the administration of the PRN opioid 30 to 45 minutes prior to painful events, such as personal care, to maximize Mrs T.'s comfort with movement.[26,35]

The RN discusses the plan of care with the team. Staff members are alerted to the need to document Mrs T.'s response to the pain medication and determine the effectiveness on the medication record using the PAINAD. Certified nursing assistants are asked to carefully document any behaviors, old or new, that suggest pain. Mrs T.'s plan of care and medications will be reviewed each day over the next 5 days. If additional medication changes are indicated, the RN will notify the hospice medical director.

The RN calls the ALH owner and discusses her assessment of Mrs T., indicating why she suspects pain is at least one cause for the behaviors. She educates the

ALH owner on behavioral signs of pain in persons with dementia and offers to teach the ALH caregivers how to use the PAINAD. She instructs the caregivers to routinely administer the prescribed analgesic medications to maximize Mrs T.'s comfort and report their observations of Mrs T.'s responses. In reply to the previous requests for haloperidol or quetiapine, the RN educates the ALH owner that antipsychotic medications are not warranted because Mrs T. is not demonstrating any psychotic signs and symptoms or persistent extreme episodes of agitation. She goes on to explain that antipsychotic medications do not target pain, pose significant morbidity and mortality risks to patients with dementia, and should be used only when absolutely necessary.[51,52]

The direct caregivers are taught how to use the PAINAD tool and observe pain behaviors. The RN requests that the caregivers report the PAINAD score after analgesic medications are administered to evaluate the effectiveness of the intervention. She also asks the caregivers to list the types of nonpharmacological methods they could use to enhance Mrs T.'s comfort. Because the caregivers know Mrs T. and have learned about her lifelong preferences from the *About Me* form, they mention that Mrs T. loves to talk about her accomplishments as a teacher and listen to Patsy Cline's music. They also note that slowly reciting the Lord's Prayer with Mrs T. appears to provide solace. One of Mrs T.'s favorite snacks is chocolate, and her face expresses a calm delight when she is having her hands massaged with lotion. The RN encourages the caregivers to trial reciting the prayer before they begin any tasks, to use sensory methods to provide meaningful connection with Mrs T. and enhance feelings of serenity. The caregivers mention they will try giving Mrs T. chocolate to help distract her during tasks and observe how she responds to the staff singing along with Patsy Cline music to lift her spirits.

Follow-up reports from the direct caregivers indicate Mrs T. no longer demonstrates resistive or distressing behaviors during personal care, and her PAINAD score = 0. Additionally, the ALH owner reports the patient rarely wakes in the middle of the night and calls out. On occasions, when Mrs T. does yell out at night, caregivers observe her for pain and provide analgesics when indicated. Additionally, they say her favorite prayer and provide a brief soothing hand massage to help her find peace and comfort. Upon witnessing Mrs T.'s positive responses to all of the interventions, the caregivers expressed a heightened awareness of how pain can influence behaviors in patients with dementia and began using the PAINAD with their other cognitively impaired residents. Inspired by Mrs T.'s favorable responses to the sensory and spiritual interventions, the caregivers noted its feasibility for positively influencing everyone and began integrating similar nonpharmacological methods customized to the lifelong preferences of their residents.

In Review—Lessons Learned

Owing to the devastating neurodegenerative changes that occur with the progression of dementia, persons with advanced dementia are vulnerable and dependent on others to provide all of the needs they can no longer obtain for themselves. Nursing theories explain what caregivers and professional staff witness when persons with dementia attempt to communicate their needs. Best practices encourage caregivers to be mindful that persons with dementia have lowered stress thresholds as a result of decreasing cognitive abilities to process, interpret, and respond to stimuli. Therefore, caregiving efforts must accommodate for the impaired abilities of the patient and modify stimuli to maximize comfort. Moreover, caregivers must acknowledge that behaviors in persons with dementia have meaning. Behaviors may serve as an effective signal to alert and compel caregivers to search for sources of discomfort in body, mind, or spirit. When determining underlying causes for behaviors, keep in mind the numerous factors that may form a differential diagnosis. Gather evidence from direct caregivers to paint a complete picture of all the details related to the behavioral episodes such as the exact behaviors observed and the time and place where behaviors occur. Explore possible causes one by one starting with the most probable, examine the patient, and review the medical history. Rule out or address delirium and other physical causes, and take into account possible environmental and caregiver triggers. Consider that the patient may be experiencing pain and exhibiting a response to discomfort with an atypical presentation. Consistently use a pain tool and trial analgesic medications when indicated. Frequently reevaluate interventions to make certain they are effective.

It is our moral and ethical responsibility to do our best to alleviate suffering. The proliferation of tools to assess for pain and the numerous pharmacological and nonpharmacological options for maximizing comfort in persons with advanced dementia enhance our abilities to fulfill our professional commitments. Integrating the aforementioned evidence-based approaches will empower caregivers to bring the best of themselves, blending both the art and science of healthcare, to maximize comfort, enhance quality of life, and elevate care practices for persons with advanced dementia.

References

1. Alzheimer's Association. *Alzheimer's Disease Facts and Figures 2010.* http://alz.org/national/documents/report_alzfactsfigures2010.pdf. Accessed August 12, 2010.
2. Alzheimer's Disease International. *World Alzheimer's Report 2010: The Global Economic Impact of Dementia.* http://www.alz.org/documents/national/World_Alzheimer_Report_2010.pdf. Accessed October 2, 2010.
3. Alliance for Aging Research. Preparing for the Silver Tsunami. 2006. http://agingresearch.org/content/article/detail/826. Accessed August 22, 2010.
4. Di Giulio P, Toscani F, Villani D, Brunelli C, Gentile S, Spadin P. Dying with advanced dementia in long-term care geriatric institutions: a retrospective study. *J Palliative Med.* 2008;11:1023-1028.
5. Mitchell SL, Kiely DK, Hamel MB. Dying with advanced dementia in the nursing home. *Arch Intern Med.* 2004;164(3):321-326.
6. Mitchell S, Teno J, Kiely D, et al. The clinical course of advanced dementia. *N Engl J Med.* 2009;361:1529-1538.
7. Sachs GA, Shega JW, Cox-Hayley D. Barriers to excellent end-of-life care for patients with dementia. *J Gen Intern Med.* 2004;19:1057-1063.
8. Shega J, Rudy T, Keefe F, Perri L, Mengin O, Weiner D. Validity of pain behaviors in persons with mild to moderate cognitive impairment. *J Am Geriatr Soc.* 2008;56(9):1631-1637.
9. Melnyk BM, Fineout-Overholt E. *Evidence-Based Practice in Nursing and Healthcare: A Guide to Best Practice.* Philadelphia, PA: Lipincott Williams and Wilkins; 2005.
10. Hall G, Buckwalter K. Progressively Lowered Stress Threshold: a conceptual model for care of adults with Alzheimer's disease. *Arch Psychiatr Nurs.* 1987;1(6):399-406.
11. Algase DL, Beck C, Kolanowski A, et al. Need-driven dementia-compromised behavior: an alternative view to disruptive behavior. *Am J Alzheimers Dis Other Demen.* 1996;11(6):10-19.
12. Kovach CR, Noonan PE, Schlidt AM, Wells T. A model of consequences of need-driven dementia-compromised behavior. *J Nurs Scholarship.* 2005;37(2):134-140.
13. Kovach CR, Noonan PE, Griffie J, Muchka S, Weissman DE. The assessment of discomfort in dementia protocol. *Pain Manage Nurs.* 2002;3(1):16-27.
14. Kovach CR, Noonan PE, Schlidt AM, Reynolds S, Wells T. The serial trial intervention an innovative approach to meeting needs of individuals with dementia. *J Gerontol Nurs.* 2006;32(4):18-25.
15. Colombo M, Vitali M, Cairati R, Vaccaro G, Andreoni A, Guaita L. Behavioral and psychotic symptoms of dementia (BPSD) improvements in a special care unit: a factor analysis. *Arch Gerontol Geriatr.* 2007;44:113-120.
16. Cooper C, Selwood A, Blanchard M, Livingston G. Abusive behavior experienced by family carers from people with dementia: the CARD (caring for relatives with dementia) study. *J Neurol Neurosurg Psychiatry.* 2010;81(6):592-596.
17. Lyketsos CG, Steinberg M, Tschanz JT, Norton MC, Steffens DC, Breitner JC. Mental and behavioral disturbances in dementia: findings from the Cache County study on memory in aging. *Am J Psychiatry.* 2000;157:708-714.
18. Gerdner L, Buckwalter K, Hall G. Temporal patterning of agitation and stressors associated with agitation: case profiles to illustrate the Progressively Lowered Stress Threshold model. *J Am Psychiatr Nurs Assoc.* 2005;11:215-222.
19. Fick D, Mion L. Delirium superimposed on dementia: an algorithm for detecting and managing this underrecognized confluence of conditions. *Am J Nurs.* 2008;108(1):52-60.
20. Inouye SK. Delirium in older persons. *N Engl J Med.* 2006;354:1157-1165.
21. Breitbart W, Strout D. Delirium in the terminally ill. *Clin Geriatr Med.* 2000;16:357-372.
22. Casarett D, Inouye SK. Diagnosis and management of delirium near the end of life. *Ann Intern Med.* 2001;135:32-40.
23. Fick DM, Agostini JV, Inouye SK. Delirium superimposed on dementia: a systematic review. *J Am Geriatr Soc.* 2002;50:1723-1732.
24. Cole MG. Delirium in elderly patients. *Am J Geriatr Psychiatry.* 2004;12:7-21.
25. Fick D, Hodo D, Lawrence FG, Inouye SK. Recognizing delirium superimposed on dementia: assessing nurses' knowledge using case vignettes. *J Gerontol Nurs.* 2007;33(2):40-47.
26. American Geriatrics Society [AGS] Panel on the Pharmacological Management of Persistent Pain in Older Persons. Pharmacological management of persistent pain in older persons. *J Am Geriatr Soc.* 2009;57(8):1331-1346.
27. Dougherty J, Gallagher M, Cabral D, Long CO, McLean A. *About Me*: knowing the person with advanced dementia. *Alzheimer's Care Q.* 2007;8(1):12-16.
28. National Hospice and Palliative Care Organization (NHPCO). *Caring for Persons With Alzheimer's and Other Dementias: Guidelines for Hospice Providers.* Alexandria, VA: National Hospice and Palliative Care Organization; 2007. http://www.nhpco.org/i4a/pages/Index.cfm?pageID=5397. Accessed August 19, 2010.
29. Volicer L. End of life for people with dementia in long-term care settings. *Alzheimers Care Today.* 2008;9(2):84-102.
30. Cohen-Mansfield J, Mintzer J. Time for change: the role of nonpharmacological interventions in treating behavior problems in nursing home residents with dementia. *Alzheimers Dis Assoc Disord.* 2005;19(1):37-40.
31. Kitwood T. *Dementia Reconsidered.* London: Open University Press; 1997.
32. Herr K. Pain in the older adult: an imperative across all health care settings. *Pain Manage Nurs.* 2010;11(2):S1-S10.
33. Won A, Lapane G, Vallow S. Persistent non-malignant pain and analgesic prescribing patterns in elderly nursing home residents. *J Am Geriatr Soc.* 2004;52:867-874.
34. Herr K, Coyne PJ, Manworren R, et al. Pain assessment in the nonverbal patient: position statement with clinical practice recommendations. *Pain Manage Nurs.* 2006;7(2):42-52.
35. Horgas A, Elliott A, Marsiske M. Pain assessment in persons with dementia: relationship between self-report and behavioral observation. *J Am Geriatr Soc.* 2009;57(1):126-132.
36. American Geriatrics Society [AGS] Panel on the Management of Persistent Pain in Older Persons. AGS panel on persistent pain in older persons. *J Am Geriatr Soc.* 2002;50:S205-S224.
37. Chibnall J, Tait R, Harman B, Luehbert R. Effect of acetaminophen on behavior, well-being, and psychotropic medications use in nursing home residents with moderate-to-severe dementia. *J Am Geriatr Soc.* 2005;53:1921-1929.
38. Bjoro K, Herr K. Assessment of pain in the nonverbal or cognitively impaired older adult. *Clin Geriatr Med.* 2008;24(2):237-262.
39. Benedetti F, Arduino C, Vighetti S, Asteggiano G, Tarenzi L, Rainero I. Pain reactivity in Alzheimer's patients with different degrees of cognitive impairment and brain electrical activity deterioration. *Pain.* 2004;111(1-2):22-29.
40. Rainero I, Vighetti S, Bergamasco B, Pinessi L, Benedetti F. Autonomic responses and pain perception in Alzheimer's disease. *Eur J Pain.* 2000;4(3):267-274.
41. Benedetti F, Arduino C, Costa S, et al. Loss of expectation-related mechanisms in Alzheimer's disease makes analgesic therapies less effective. *Pain.* 2006;121(1-2):133-144.
42. Derby S, O'Mahony S, Tickoo R. Chapter 38. Elderly patients. In: Ferrell BR, Coyle N, eds. *Oxford Textbook of Palliative Nursing.* 3rd ed. New York: Oxford University Press; 2010:713-743.
43. Herr K, Bursch H, Ersek M, Miller LL, Swafford K. Use of pain-behavioral assessment tools in the nursing home. *J Gerontol Nurs.* 2010;36(3):18-29.
44. Cepeda MS, Carr DB, Lau J, Alvarez H. Music for pain relief. *Cochrane Database Syst Rev.* 2006;(2):Art. no.:CD004843. DOI: 10.1002/14651858.CD004843.pub2.

45. Gerdner L. Evidence-based guidelines: individualized music for elders with dementia. *J Gerontol Nurs*. 2010;36(6):7-15.
46. Park H. Effect of music on pain for home-dwelling persons with dementia. *Pain Manage Nurs*. 2009;8:1-7.
47. Roff LL, Parker MW. Spirituality and Alzheimer's disease care. *Alzheimer's Care Q*. 2003;4(4):267-270.
48. Tilly J, Reed P, Gould E, Fok A. *Dementia Care Practice Recommendations for Assisted Living and Nursing Homes-Phase 3: End of Life Care*. 2007; http://www.alz.org/national/documents/brochure_DCPRphase3.pdf. Accessed August 2, 2010.
49. Pasero C, McCaffery M. *Pain Assessment and Pharmacologic Management*. St Louis, MO: Elsevier Mosby; 2011.
50. Herr K, Bjoro K, Decker S. Tools for assessment of pain in nonverbal older adults with dementia: a state-of-the-science review. *J Pain Symptom Manage*. 2006;31:170-192.
51. Ballard C, Hanney ML, Theodoulou M, et al. The dementia antipsychotic withdrawal trial (DART-AD): long-term follow-up of a randomized placebo-controlled trial. *Lancet Neurol*. 2009;8(2):151-157.
52. Jeste D, Blazer D, Casey D, et al. ACNP white paper: update on use of antipsychotic drugs in elderly persons with dementia. *Neuropsychopharmacology*. 2008;33:957-970.
53. Warden V, Hurley AC, Volicer L. Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *J Am Med Dir Assoc*. 2003;4:9-15.

For more than 90 continuing nursing education articles on palliative care topics, go to NursingCenter.com\CE.