
■ CHAPTER 6 ■

Older Adults With Severe Cognitive Impairment: Assessment of Pain

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Revised and reprinted from
Annals of Long-Term Care: Clinical Care and Aging 2004; 12(4):46-52

Despite the prevalence and consequences of pain among older adults, pain is inadequately recognized and treated, especially in those with severe cognitive impairment. Among the barriers to assessment of pain in this challenging population are the inability of some older patients to communicate their pain experience and the misconception that pain is less severe in those with cognitive impairment.

Although continued research is needed to evolve the evidence for best practices, current guidelines and research can provide recommendations to improve assessment practices when caring for this vulnerable population. Use of surrogate reporters, direct observation of potential pain indicators, monitoring for changes in baseline activity patterns, and ruling pain out as a possible cause of behaviors through nondrug and analgesic trials are identified as key elements of an approach to assessing pain in those with severe cognitive impairment.

INTRODUCTION

More than 1.5 million Americans live in nursing homes, a number that will dramatically increase in the next two decades, and up to 80% of long-term care facility residents experience substantial pain (Baer & Hanson, 2000; Ferrell, Ferrell, & Rivera, 1995; Won, Lapane, Vallow, Schein, Morris, et al., 2004). Because pain is often remediable (American Geriatrics Society (AGS), 2002), it is thought that the high prevalence estimates of unrelieved pain in older persons may result from underrecognition, which in turn results in undertreatment (Horgas & Tsai, 1998; Morrison & Siu, 2000; Weiner, Peterson, Ladd, McConnell, & Keefe, 1999). Unrecognized and thus untreated (or undertreated) pain can have serious consequences for the quality of life of older persons. Unrelieved pain has been associated with altered immune function, impaired psychological function (e.g., depression, anxiety, fear), impaired physical function (e.g., impaired mobility and gait, delayed rehabilitation, falls), sleep disturbance, compromised cognitive function, and decreased socialization (AGS, 2002; Brummel-Smith, London, Drew, Krulewitch, Singer, et al., 2002; Hartikainen, Mantyselka, Louhivuori-Laako, & Sulkava, 2005; Herrick et al., 2004; Jakobsson, Rahm Hallberg, & Westergren, 2004; Landi et al., 2005; Schuler, Njoo, Hestermann, Oster, & Hauer, 2004; Weiner, Herr, & Rudy, 2002). These negative consequences can result in increased dependency and helplessness, as well as increased use of health care resources, and eventually in increased costs. In those with severe cognitive impairment, these outcomes are often attributed to other conditions, such as dementia, rather than to unrecognized and untreated painful conditions. The ultimate impact of pain on quality of life in this population is difficult to determine (Brummel-Smith et al., 2002).

Despite the prevalence and consequences of pain among older adults, health care professionals remain ineffective at both its assessment (Hall-Lord, Larrson, & Steen, 1998; Herr et al., 2004; Weiner, Peterson, & Keefe, 1999) and its treatment (Bernabei et al., 1998; Morrison & Siu, 2000; Teno, Weitzen, Wetle, & Mor, 2001; 2004; Won et al., 2004), especially in those who are unable to communicate their discomfort. Older adults with cognitive impairment receive less pain medication than those who are able to communicate, even though they are just as likely to experience painful

illnesses. Studies have also shown that those with more disorientation and functional impairment receive fewer analgesics (Feldt, Ryden, & Miles, 1998; Horgas & Tsai, 1998; Morrison & Siu, 2000; Won et al., 2004). Multiple factors contribute to poor pain management in this population; however, the most troublesome is the failure to recognize pain in elders who cannot communicate their pain experience (Herr, Bjoro, & Decker, in press). Therefore, it is imperative that health care professionals' knowledge and skills related to pain assessment in older adults be improved and aggressive approaches to comprehensive pain assessment be adopted.

BARRIERS TO PAIN ASSESSMENT IN OLDER ADULTS WITH SEVERE COGNITIVE IMPAIRMENT

Awareness of barriers that interfere with effective assessment and management of pain is important in developing a plan of care that promotes comfort in the older adult. The most obvious barrier is the inability of the person with severe dementia to communicate the presence of pain, at least in a manner that is easily understood, and to assist in the differentiation of pain etiologies. This necessitates alternative approaches to assessment in this population, which are discussed below.

Although a number of misconceptions and fears have been commonly identified in older adults (Herr & Garand, 2001), it is the misconceptions and lack of knowledge of the patient's family/significant other and the health care provider that must be addressed in order to provide quality pain assessment and intervention to patients with severe cognitive impairment. A major misconception that affects recognition of pain in this population is the belief that cognitively impaired older adults do not experience pain as severely as those who are intact. There is no convincing evidence that peripheral nociceptor responses or pain transmission are impaired in people with dementia, although controversy does exist about central nervous system changes that influence or diminish interpretation of pain transmission (Gibson, Voukelatos, Ames, Flicker, & Helme, 2001; Scherder, Slaets, Deijen, Gorter, Ooms, al., 2003; Schuler et al., 2004). People with dementia may have altered affective responses to pain, probably due to their inability to cognitively process the painful sensation in the context of prior pain experience, attitudes, knowledge, and beliefs

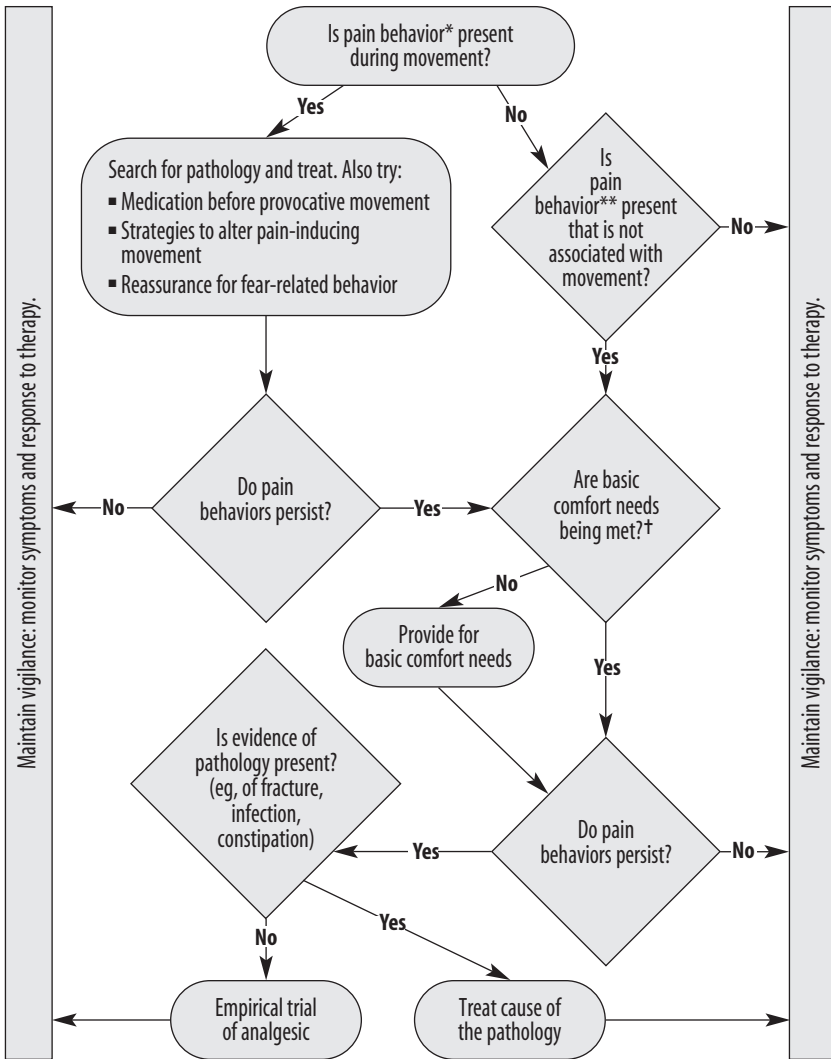
(Scherder, Oosterman, Swaab, Herr, Ooms et al., 2005). Reactions to painful sensations may differ from the typical response expected from a cognitively intact older person. For example, constipation can cause great distress in the cognitively impaired older patient and may lead to aggressive or agitated behaviors. Thus, until evidence establishes that those with dementia experience less pain, we should assume that any condition that is painful to a cognitively intact person would also be painful to those with advanced dementia who cannot express themselves. This assumption has implications for the recognition and management of pain in this population. Knowledge of possible indicators of pain presence in the older adult with severe cognitive impairment and strategies for assessment are key. Integration of content into health care that provides curricula, continuing education for current providers, and family/caregiver education is essential.

ASSESSMENT APPROACHES FOR OLDER PERSONS WITH SEVERE COGNITIVE IMPAIRMENT

The AGS Panel on Persistent Pain (2002) and the American Medical Directors Association (2003) have developed guidelines to address the needs of older adults with persistent pain in a variety of settings. These guidelines provide assistance to clinicians with decision-making responsibilities regarding pain assessment and management in older persons, although additional research is needed to further refine recommendations related to those with severe cognitive impairment. Figure 1 presents a practical approach to evaluating the presence of pain in the nonverbal cognitively impaired older patient (Reuben et al., 2005).

While evidence exists that older adults with cognitive impairment can complete self-report pain scales (Chibnall & Tait, 2001; Closs, Barr, Briggs, Cash, & Seers, 2004; Herr, Spratt, Mobily, & Richardson, 2004; Kaasalainen & Crook, 2003; Scherder et al., 2003; Taylor & Herr, 2003; Taylor, Harris, Epps, & Herr, 2005), a challenge remains in assessing pain in older adults who experience more severe cognitive decline associated with a loss of language skills. Whereas self-report of pain is the gold standard for pain assessment, other approaches are necessary in this population, such as observational and surrogate reports. Although a precise and accurate method for interpreting the expression of pain in persons with cognitive

FIGURE 1. ALGORITHM FOR THE ASSESSMENT OF PAIN IN ELDERLS WITH SEVERE COGNITIVE IMPAIRMENT



* Eg, grimacing, guarding, combativeness, groaning with movement; resisting care.

** Eg, agitation, fidgeting, sleep disturbance, diminished appetite, irritability, reclusiveness, disruptive behavior, rigidity, rapid blinking.

† Eg, toileting, thirst, hunger, visual or hearing impairment.

Note. From Reuben, DB, Herr, KA, Pacala JT, et al. *Geriatrics At Your Fingertips: 2005*, 7th Edition, p. 142. The American Geriatrics Society; 2005. Used with permission.

impairment is not available, recommendations can be made to guide practice decisions and provide a framework to guide future research in this important area.

DIRECT OBSERVATION: SURROGATE REPORTERS

When older patients are unable to use traditional self-report pain instruments, direct observation by health care providers and eliciting information from surrogates (family members, aides) is essential (AGS, 2002). It can be difficult to recognize that certain behaviors may indicate pain if the health care provider is unfamiliar with how the person usually behaves. Caregivers can be very helpful in recognizing changes in persons with dementia that might indicate pain. Caregivers with the most direct and long-standing relationship with the patient are in the best position to recognize subtle changes and communicate them to the health care provider (Cohen-Mansfield & Creedon, 2002). However, surrogate reporters must have preparation and training regarding the types of behaviors and activity changes that might indicate pain.

Although studies of pain behavior observation protocols suggest that well-trained surrogate ratings of pain are relatively accurate (Dirks, Wunder, Kingsman, McElhinny, & Jones, 1993; Richards, Nepomuceno, Riles, & Suer, 1982; Weiner, Peterson, & Keefe, 1999), outcomes for health care and family surrogates are much more disappointing. When patient self-reported pain ratings are compared with those of professional caregivers (health care surrogates), both physicians and nurses tend to underestimate the severity of the patient's pain (Cohen-Mansfield & Lipson, 2002; Fisher et al., 2002; Hall-Lord et al., 1998; Horgas & Dunn, 2001; Weiner, Peterson, & Keefe, 1999). While family caregivers are more adept at estimating the pain of others, they tend to overestimate the intensity of pain (Cohen-Mansfield, 2002; Yeager, Miaskowski, Dibble, & Wallhagen, 1995). Although surrogate reporters have difficulty accurately identifying the severity of pain from behavioral observation, they are able to recognize the presence of pain (Manfredi, Breuer, Meier, & Libow, 2003; Shega, Hougham, Stocking, Cox-Hayley, & Sachs, 2004). Certified nursing assistants (CNAs) are more familiar with residents, can identify pain in this population, and play an important role in recognizing pain (Closs, Cash,

Barr, & Briggs, 2005; Fisher et al., 2002; Mentes, Teer, & Cadogan, 2004). Clearly, further investigative efforts are needed to refine the process of surrogate pain rating. However, until a more reliable method of detecting pain in noncommunicative older patients is determined, direct observation of patient behavior and surrogate reporting of pain are essential in our efforts to determine the presence of pain in this population.

PAIN INDICATORS: NONVERBAL CUES AND CHANGES IN USUAL ACTIVITY

Because most persons with advanced dementia are unable to verbally report their pain experience, observation of behaviors and activities that may indicate pain is a key assessment strategy. Caregivers should be alert for the presence of typical pain behaviors, as well as those that are less obvious and not usually attributed to pain. Table 1 includes a detailed list of common behaviors of cognitively impaired older adults who are in pain (AGS, 2002). Table 2 provides take-home pearls regarding the assessment of pain in this challenging population. Some typical pain behaviors are rubbing, guarding, moaning, groaning, crying, grimacing, and frowning. In noncommunicative older adults with severe cognitive impairment, common pain behaviors may be absent or difficult to interpret, and it is important to be alert for less obvious potential indicators of pain. For example, some forms of dementia tend to mute facial expression, while other forms of dementia appear not to affect facial expressions at all (Asplund, Norberg, Adolfsson, & Waxman, 1991). Also, agitation and disturbing or aggressive behaviors attributed to dementia actually may be indicators of pain (Buffum, Miaskowski, Sands, & Brod, 2001; Kovach, Noonan, Griffie, Muchka, & Weissman, 2001). Observation for pain behaviors at rest can be misleading, with increased indicators of pain observed during activities such as transferring, ambulating, and repositioning (Feldt, 2000; Feldt, Ryden & Miles, 1998; Hadjistavropoulos, LaChapelle, MacLeod, Snider, & Craig, 2000; Weiner, Pieper, McConnell, Martinez & Keefe, 1996). Thus, observation for indicators of pain should include active times.

More subtle and less specific nonverbal indicators of pain may include facial expressions (e.g., distorted expressions, rapid blinking,

TABLE 1. COMMON PAIN BEHAVIORS IN COGNITIVELY IMPAIRED ELDERLY PERSONS

Facial expressions

- Slight frown; sad, frightened face
 - Grimacing, wrinkled forehead; closed or tightened eyes
 - Any distorted expression
 - Rapid blinking
-

Verbalizations and vocalizations

- Sighing, moaning, groaning
 - Grunting, chanting, calling out
 - Noisy breathing
 - Asking for help
 - Verbally abusive
-

Body movements

- Rigid, tense body posture
 - Guarding
 - Fidgeting
 - Increased pacing, rocking
 - Restricted movement
 - Gait or mobility changes
-

Changes in interpersonal interactions

- Refusing food, appetite change
 - Increase in rest periods
 - Sleep/rest pattern changes
 - Sudden cessation of common routines
 - Increased wandering
-

Mental status changes

- Crying or tears
 - Increased confusion
 - Irritability or distress
-

Note. Some patients demonstrate little or no specific behavior associated with severe pain. From "The management of persistent pain in older persons," by the American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002, *Journal of the American Geriatrics Society*, 50, pp. S205-S224. Used with permission.

frightened face); verbalizations/vocalizations (e.g., grunting, chanting, verbally abusive, yelling out); body movements (e.g., fidgeting, increased pacing or rocking, rigid posture); changes in interpersonal interactions (e.g., aggressive, resisting care, disruptive, withdrawn); changes in activity patterns or routines (e.g., sudden cessation of common routines, refusing food, increased sleep, increased wandering); and mental status changes (e.g., increased confusion, irritability, distress) (Table 2) (AGS, 2002; Closs et al., 2005; Cohen-Mansfield & Creedon, 2002; Fuchs-Lacelle & Hadjistavropolous, 2004; Hadjistavropolous & Craig, 2002; Kovach, Weissmann, Griffie, Matson, & Muchka, 1999; Manfredi, Breuer, Meier, Libow, 2003). Establishing the individual's typical or baseline pattern of behavior and activity is essential in being able to recognize changes that may reflect unrecognized pain problems. For example, pain should be considered as one potential etiology if the older person with advanced dementia shows decreased activity or increased activity, change in appetite or intake, change in mood, increased agitation or restlessness, increased pacing or wandering, combativeness or aggressive behaviors, withdrawal or isolation, or increase in verbal outbursts/screaming. Although subtle changes in usual patterns of behavior or activity do not always mean that the patient is in pain, they raise the suspicion and should lead to thorough evaluation for possible pain-causing problems.

BEHAVIORAL PAIN TOOLS

Persons with cognitive impairment present with a unique "pain signature." Whereas one patient may become withdrawn and quiet, another may become agitated. Both of these behavior patterns could indicate pain, but they are difficult to reconcile with behavioral tools that attempt to score behaviors by pain intensity and that are narrow in the indicators included. In an effort to enhance the validity and reliability of behaviors for quantifying pain in older adults with severe cognitive impairment, assessment approaches that focus on behavioral observation are being developed and evaluated. Tools and approaches most readily recognized in the literature include the Discomfort in Dementia of the Alzheimer's Type (DS-DAT) (Hurley, Volicer, Hanrahan, Houde, & Volicer, 1992), the Modified DS-DAT (Miller et al., 1996); the Checklist of Nonverbal Pain

Indicators (CNPI) (Feldt, 2000); and the Assessment of Discomfort in Dementia (ADD) Protocol (Kovach, Noonan, Griffie, Muchka, & Weissman, 2002). In addition, several other tools are available to assess pain in this population, including the Pain Assessment in Advanced Dementia (PAINAD) scale (Warden, Hurley, & Volicer, 2003); the Nursing Assistant-Administered Instrument to Assess Pain in Demented Individuals (NOPPAIN) (Snow, Weber, O'Malley, Cody, Beck, 2004) and the Pain Assessment Checklist for Seniors with Severe Dementia (PACSLAC) (Fuchs-Lacelle & Hadjistravropolous, 2004). Several promising approaches to behavioral assessment in the nonverbal, cognitively impaired older adult exist, but most are in the early stages of testing or are limited in their clinical utility. These tools and approaches have various strengths and limitations related to the available evidence to support their use in clinical practice. A state-of-the-science review of available nonverbal assessment tools is available to guide the clinician in selecting a tool appropriate for the patient and setting (Herr, Bjoro & Decker) in press).

The testing of existing behavioral observation assessment instruments in minority older adults with dementia is limited. With an increase in cultural diversity in the United States (Administration on Aging, 2003; Hayward & Zhang, 2001); an increase in dementia among minority populations (Alzheimer's Disease International, 1999); and evidence that minority patients are undertreated (Bernabei et al., 1998; Teno, Kabunoto, Wetle, Roy, & Mor, 2004; Won, Lapene, Gambassi, Bernabei, Mor, et al., 1999), it is important for researchers to extend development and evaluation of observational assessment tools to address minority older adults with dementia.

SEARCH FOR CAUSES OF PAIN/DISCOMFORT

If pain behaviors or activity changes are observed, the practitioner should attempt to determine whether pain is the etiology, as many of these nonspecific behaviors (e.g., agitation, restlessness, yelling, withdrawal, pacing) could be related to other causes or to the disease process of dementia. When pain is suspected, a search for possible causes is important to guide treatment decisions. Common problems (e.g., constipation, inflammation, infection, fractures, pressure ulcers) or procedures

TABLE 2. TAKE-HOME PEARLS

- 1.** Health care providers and caregivers/families often harbor myths and misconceptions about pain and its treatment in the nonverbal elder with severe cognitive impairment that must be recognized and debunked.
- 2.** The most common reason that pain is undertreated in older adults is failure to assess it.
- 3.** Older persons often have multiple persistent pain problems that must be considered in evaluation of new and ongoing pain conditions.
- 4.** Alternative strategies are important when assessing pain in older persons who cannot communicate their pain.
- 5.** Subtle pain behaviors or changes in routine/activities may be indicators of the presence of pain in those with severe cognitive impairment.
- 6.** If behavioral changes are noted, assume that pain is present until proven otherwise.
- 7.** If you would experience pain in similar circumstances, assume that the nonverbal cognitively impaired person would as well.
- 8.** Use of pain treatments (e.g., pharmacologic and nonpharmacologic approaches) plays a key role in evaluating for the presence of pain in persons who cannot communicate.
- 9.** Involvement of family and/or caregivers may be useful in recognizing changes in behavior/activities that may suggest the presence of pain.
- 10.** Teach family members and caregivers about the relationship between behavioral and activity changes and pain to facilitate their help in pain assessment.
- 11.** Regular reassessment is essential to evaluate and monitor response to pain interventions and to recognize the return of pain or new pain problems.
- 12.** The same scale and behavioral manifestations used to identify pain in older persons should be used in evaluating the effectiveness of interventions.
- 13.** Identified pain behaviors (specific and nonspecific) must be communicated to other health care providers and across care settings.

Source: Keela Herr and Sheila Decker

(e.g., dressing changes) that are known to be uncomfortable should be considered as possible causes of changes in behavior (Morrison, Ahronheim, Morrison, Darling, Baskin, et al., 1998). A number of chronic pain problems prevalent in older adults should be considered when exploring possible pain etiologies. For example, up to 80% of older adults experience osteoarthritis, so this is a common reason for pain in this population. Other conditions that should be considered are inflammatory arthritis, neuralgias (e.g., postherpetic neuralgia, trigeminal neuralgia), peripheral neuropathy (ischemic and diabetic), temporal arteritis and polymyalgia rheumatica, osteoporosis-related compression fractures, low back pain, spinal stenosis, old and undiagnosed fractures, myofascial pain syndromes, post-stroke syndrome, phantom limb pain, and many types of cancer (Donald & Foy, 2004; Weiner & Herr, 2002). If the patient has a disease that would be painful to others who can verbalize, assume that it is painful for the person with advanced dementia. Efforts should focus on treating any identifiable pathologies and premedicating before painful procedures. If physical causes are ruled out, interventions should focus on basic comfort measures (such as positioning, toileting, soothing communication, addressing hunger and thirst, managing environmental stimuli) and addressing unmet needs (Kovach et al., 2002; Miller et al., 1996). Sources of environmental stress (e.g., loud noises, glare from lights, poorly fitting clothes or shoes), balance between rest and activity, and level of human interaction should be considered (Kovach et al., 2002).

ANALGESIC TRIAL

If pain behaviors continue after other possible causes are ruled out or treated, an empiric analgesic trial is warranted as an assessment approach. Because it is difficult to determine the level of pain severity in persons with advanced dementia, selection of an appropriate analgesic is challenging. The few studies that have examined use of an analgesic trial start with a nonopioid such as acetaminophen 500-1000 mg three times a day (Buffum, Sands, Miaskowski, Brod, & Washburn, 2004; Douzjian et al., 1998; Kovach et al., 1999; 2002). However, titration to higher doses and stronger analgesics may be necessary before ruling out pain as the etiology for behavior or activity changes (Manfredi, Breuer, Wallenstein et al., 2003).

If interventions appear to result in pain relief (e.g., decreased agitation or restlessness), assume that pain was the likely cause and continue pharmacologic and/or nonpharmacologic interventions. If behavioral changes persist or intensify, continue to rule out and focus treatment on other possible causes, such as delirium, adverse effects of treatment, and drug metabolite accumulation.

Preliminary research on the use of an analgesic trial as part of the protocol for assessing the presence of pain in the noncommunicative older adult suggests that this approach can reduce pain-related behaviors (Kovach et al., 2002; Manfredi, Breuer, Meier et al., 2003), although further research in controlled studies is needed to develop an algorithm to guide practice decisions.

REASSESSMENT AND COMMUNICATION STRATEGIES

Reassessment of pain and other symptoms, using the same assessment approach, should be conducted at regular intervals at times that relate to the anticipated peak and duration of administered analgesics. Because recognition of subtle changes in behavior is difficult for anyone without an ongoing history/knowledge of the individual patient's usual behavior pattern, any specific behaviors or activity changes that are being monitored must be communicated to other health care providers and caregivers to ensure continuity of care when the older person with severe cognitive impairment is moving between care providers or care settings. Development of a transfer document or communication approach (e.g., faxed information sheet) that incorporates this individualized assessment would be helpful to ensure communication of essential information.

SUMMARY

Although the science to guide pain assessment practices in older adults with severe cognitive impairment is still evolving, adopting current recommendations for practice should improve the recognition of pain in this vulnerable population. Interventions adapted to meet the needs of frail older adults must follow to improve comfort and quality of life for these elders in their final stage of life. ■

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Sheila Decker earned her PhD in nursing from Saint Louis University, St. Louis, MO, and is a certified Gerontology Nurse Practitioner. Dr. Decker currently holds a faculty position as an Assistant Professor in the School of Nursing at The University of Texas Health Science Center-Houston. Her research interest is pain assessment and management in the elderly with dementia. She developed the Pain Assessment Tool in Confused Older Adults (PATCOA) to assess postoperative pain. Dr. Decker continues to conduct research in the area of instrument development to evaluate an instrument to assess persistent pain in elderly nursing home residents, and is extending that work to include minority elders with dementia. Her research in the area of pain management includes an interest in healing touch and massage therapy.

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