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Patients with Advanced Dementia: How Do We Know If They are in Pain?

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Introduction

Pain in people with dementia is a critical public health problem. As the population of older adults increases, hospital nurses are more likely to encounter patients with dementia admitted for acute and often painful conditions. Indeed, nearly 50% of older people admitted to the hospital report pain with approximately 20% reporting severe pain.¹ Despite years of initiatives, inadequate pain care, especially of older adults, continues to occur in hospitals.² One major barrier to the delivery of adequate pain management is the inability of nurses and physicians to determine the existence of pain in those with advanced dementia, given patients' inability to report pain.³

Background

People with mild to moderate cognitive impairment can report their pain. Those with severe cognitive impairment, however, tax clinicians' ability to detect pain.⁴ For many years, the medical community has been taught that pain is "whatever the person experiencing it says that it is, existing wherever he or she says that it does."⁵ When verbal reports are no longer possible, behavioral indicators of pain, such as a grimace, are the recommended pain assessment method. However, as dementia progresses the behavioral indicators of pain may become less reliable. Studies have shown that those with advanced dementia and known painful conditions demonstrate increased responses (such as rocking, grimacing, or groaning) but also can present with a diminished behavioral response as seen in the case study.³

Irrespective of degree of cognitive impairment, the impact of untreated pain in older people can be devastating, causing depression, anxiety, worsening cognitive impairment, slower healing, and functional loss. Because people with advanced dementia may have chronic and/or acute untreated pain, they are more likely to suffer with these conditions compared with those who are able to express their pain.

Recommendations

To assist nurses and physicians, 2 pain behavioral assessment tools were recently recommended for clinical use in nonverbal older adults in the nursing home,⁶ the PAINAD⁷ and the Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC).⁸ The PAINAD has also been successfully used in hospitalized adults with limited ability to communicate.⁹

The PAINAD is an observational tool that lists 5 types of behaviors: breathing, negative vocalization, facial expression, body language, and consolability. For each behavior, descriptors are provided that range in severity from 0 (normal or none) to 2 (behavior is very pronounced). The score is summed for a potential range of 0 to 10 (Figure 1). A score of 1 on the PAINAD was found to be associated with “probable” pain. A score of 2 was determined to be an indicator of possible pain requiring a trial for pain treatment.¹⁰ Notably, the 0 to 10 pain behavior scoring system on the PAINAD should not be confused with a 0 to 10 pain severity score on a numerical rating scale (NRS).¹¹ Experts contend that without self-report, determining pain severity is not possible.

Conclusions

Additional research needs to focus on the neurobiology, assessment, and management of pain in people who cannot reliably report pain. Because limited evidence exists regarding the neurophysiology of pain in nonverbal people with advanced dementia, clinicians should not assume that nonexpression of pain equates to absence of pain. If you are providing care to an individual with dementia who has a condition or procedure known to be painful, be mindful that this person may be suffering. Contact the primary care provider to determine usual behavior in a person with dementia. Behavioral assessment tools cannot determine the severity of pain, but they are recommended as 1 component of a comprehensive pain assessment protocol (for more information, see consultgerim.org/uploads/File/trythis/try_this_d2.pdf).

Biographies

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Case Study

Mr. Hunter is an 87-year-old gentleman residing in a long-term care facility. He has been diagnosed with Alzheimer's for more than 10 years. On occasion he attempts to ambulate and he requires assistance with bathing, dressing, and toileting. His speech has deteriorated to only repetitive monosyllabic noises. Mr. Hunter fell and sustained a right femur fracture requiring internal fixation. On the second day after surgery, the nurse noted that Mr. Hunter did not have the usual analgesic coverage. Rather, he had an order for acetaminophen (Tylenol) every 6 hours as needed. The nurse noted that Mr. Hunter was lying still and did not appear to be in distress. The nurse contacted the nursing home nurse who reported that Mr. Hunter rarely lies still. Also, the nursing home nurse explained that they assess pain using the Pain Assessment in Advanced Dementia (PAINAD) behavior tool and faxed a copy of the tool to the hospital nurse. A review of the medical chart indicated that Mr. Hunter slept intermittently the previous night, and when she conducted a physical examination, Mr. Hunter seemed "rigid" and exhibited shallow breathing at a rate of about 20 breaths per minute. The nurse used the PAINAD behavioral tool to assess Mr. Hunter's pain. She noted that Mr. Hunter exhibited a positive score for possible pain. The nurse immediately called the surgeon and received an order for 1 to 2 mg of scheduled morphine every 8 hours over the next 3 days. After the first dose, Mr. Hunter's body relaxed, and his breathing became regular at a rate of 14 per minute. Later that evening, Mr. Hunter slept 7 hours.

Pain Assessment Tool Guidelines for use: PAINAD				
Indicator	Score = 0	Score = 1	Score = 2	Total Score
Breathing:	Normal breathing	Occasional labored breathing Short period of hyperventilation	Noisy labored breathing. Long period of hyperventilation. Cheyne-Stokes respiration	
Negative vocalizations:	None	Occasional moan/groan. Low level, speech with a negative or disapproving quality	Repeated troubled calling out. Loud moaning or groaning. Crying.	
Facial Expression	Smiling or inexpressive	Sad, frightened, frown	Facial grimace	
Body Language	Relaxed	Tense, distressed, pacing, fidgeting.	Rigid, fists clenched. Knees pulled up. Striking out. Pulling or pushing away.	
Consolability:	No need to console	Distracted by voice or touch.	Unable to console, distract or reassure.	
TOTAL:				

Description: The Pain Assessment in Advanced Dementia (PAINAD) was developed to assess pain in patients who are cognitively impaired, non-communicative, or suffering from dementia and unable to use self-report methods to describe pain. Observation of patients during activity records behavioral indicators of pain: breathing, negative vocalization, facial expression, body language, and consolability.

How to use: PAINAD is a five item observational tool with numerical equivalents for each of the five behavior items listed, with total scores ranging from 0 to 10. Each of the five assessments contains a range from 0 to 2 and the summation of each of the five categories results in the total numerical score. Please refer to the attached item descriptions. To use:

- Assess patient during periods of activity, such as turning, ambulating, transferring
- Assess patient for each of the 5 indicators: breathing, negative vocalization, facial expression, body language, and consolability
- Assign a numerical point value based on each of the 5 assessments observed
- Obtain a total score, by adding scores from the 5 indicators. Total score ranges from a minimum of 0 to a maximum of 10.

Populations for use: The primary population for use of the PAINAD is the adult patient with dementia who is unable to self-report pain level.

Validity and reliability: While self-report remains the "gold standard" for pain assessment, several studies have indicated that the PAINAD is an accurate assessment tool for use in the adult patient population for whom self-report is not a reliable tool due to their altered cognitive abilities.

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PAINAD: ITEM DEFINITIONS

Breathing: *Normal breathing* is characterized by effortless, quiet, rhythmic (smooth) respirations

- Occasional labored breathing:* episodic bursts of harsh, difficult or wearing respirations.
- Short period of hyperventilation:* intervals of rapid, deep breaths lasting a short period of time.
- Noisy labored breathing:* sounds on inspiration or expiration. They may be loud, gurgling, wheezing. They appear strenuous or wearing.
- Long period of hyperventilation:* an excessive rate and depth of respirations lasting a considerable time.
- Cheyne-Stokes respirations:* rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea.

Negative Vocalization: *None* is characterized by speech or vocalization that has a neutral or pleasant quality.

- Occasional moan or groan:* Moaning is mournful or murmuring sounds, wails or laments. Groaning is louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
- Low level speech: negative or disapproving quality:* muttering, whining, or swearing in a low volume. Complaining, sarcastic or caustic.
- Repeated troubled calling out:* phrases or words being used over and over in a tone that suggests anxiety, uneasiness, or distress.
- Loud moaning or groaning:* mournful or murmuring sounds, wails or laments in much louder than usual volume. Loud groaning is characterized by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
- Crying:* an utterance of emotion accompanied by tears. There may be sobbing or quiet weeping.

Facial Expression: *Smiling* (upturned corners of the mouth with a look of pleasure or contentment) *or inexpressive* (neutral, at ease, relaxed)

- Sad:* an unhappy, lonesome, sorrowful, or dejected look. There may be tears in the eyes.
- Frightened:* a look of fear, alarm or heightened anxiety. Eyes appear wide open.
- Frown:* a downward turn of the corners of the mouth. Increased facial wrinkling in the forehead and around the mouth may appear.
- Facial grimacing:* a distorted, distressed look. The brow is more wrinkled as is the area around the mouth. Eyes may be squeezed shut.

Body Language: *Relaxed:* a calm, restful, mellow appearance. The person seems to be taking it easy.

- Tense:* a strained, apprehensive or worried appearance. The jaw may be clenched. (exclude any contractures)
- Distressed pacing:* activity that seems unsettled. May appear fearful, worried, or disturbed. Pacing may be faster or slower than usual.
- Fidgeting:* restless movement. Squirming about or wiggling, may hitch a chair across the room. Repetitive touching, tugging or rubbing.
- Rigid:* stiffening of the body. The arms and/or legs are tight and inflexible. The trunk may appear straight and unyielding. (not contractures)
- Fists clenched:* tightly closed hands. They may be opened and closed repeatedly or held tightly shut.
- Knees pulled up:* flexing the legs and drawing the knees up toward the chest. An overall troubled appearance. (exclude any contractures)
- Pulling or pushing away:* Resists attempts of others to help. Tries to escape by yanking or wrenching free or shoving helpers away.
- Striking out:* hitting, kicking, grabbing, punching, biting, or other form of personal assault.

Consolability: *No need to console:* a sense of well being. The person appears content.

- Distracted or reassured by voice or touch:* Behavior suggestive of distress stops when the person is spoken to or touched.
- Unable to console, distract or reassure:* the inability to soothe the person or stop a behavior with words or actions. No amount of comforting, verbal or physical, will alleviate the behavior suggestive of distress.

Figure 1.
Description of the PAINAD pain behavioral assessment tool with directions for suggested use.