

PAIN TOPICS

Assessment of Pain in Patients with Dementia

Kathryn Agarwal, MD

Geriatric Fellow, Harvard Medical School

Faculty Scholar, Program in Palliative Care Education and Practice, Harvard Medical School

This article first appeared in *Pain Relief Connection* Vol 1 #9, September 18, 2002. "Pain Topics" and *Pain Relief Connection* are services of MGH Cares About Pain Relief.

McCaffery has stated that "Pain is whatever the experiencing person says it is, existing whenever he says it does."¹ This conceptualization of pain emphasizes the subjective and highly individual nature of pain, but seems to exclude the patient with severe dementia because verbalization is a necessary condition for the ability to report pain. Dementia may affect the cognitive, behavioral, and emotional facets of pain.

Multiple studies have documented the under-treatment of pain in elderly patients in the community, nursing home, and acute-care settings.² For example, in elders who were recovering from hip fracture repair, cognitively impaired patients received significantly less pain medication than cognitively intact patients, all of whom reported ongoing moderate to severe levels of pain.³

How then do we assess pain in a patient with dementia? The first principle for evaluating pain in cognitively impaired patients is to believe the complaint if it is verbalized. Parmelee looked at the association between self-reported pain and cognitive impairment among frail elders. Her overall conclusions were:

1. Mildly impaired individuals were almost equally able to accurately report their pain.
2. Patient pain complaints were genuine.
3. Impaired patients with communication skills will not neglect reporting of pain when queried specifically.
4. Markedly impaired patients reported less intense pain and a smaller number of pain complaints than the mildly impaired.⁴

Where is the pain? In patients with a [Mini-Mental State Examination](#)⁵ (MMSE) score of <15, 86% could locate pain on themselves. From this and other studies, it appears that using self to locate pain is the most reliable way to locate pain in those with significant cognitive impairment.⁶

When and what type of pain? With progressive short-term memory deficits, time and aggravating factors are difficult to elicit. Studies confirm that patients with cognitive impairment give confounding reports when asked to give comparison of pain over the last 2 weeks.⁷ Some helpful tips include asking caregivers for information about time of onset, frequency and aggravating factors. Ask about pain when moving or palpating of the area thought to be painful. While at rest, the patient may not remember the pain. This was seen in a study of dementia patients post hip fracture repair: the patients would respond "no" to question of pain until moved. To determine quality, verbalize a list of adjectives such as squeezing, cramping, burning, etc. One or more may ring true with the patient.

What is the intensity of the pain? Many pain scales are validated for use in adults; however, high completion failure rates have been noted in those with mild-moderate dementia. Luckily, some studies have been done comparing different pain scales in patients with dementia. In 1995, Ferrell, et al at UCLA did a study of nursing home residents with an average age of 85, and a mean MMSE score of 12. They compared five frequently used pain scales. 83% of patients could complete at least one scale. Only one-third of the residents could complete all of the scales. Overall the authors stressed that most of the cognitively impaired residents could complete at least one bedside assessment tool, but significant patience and time may be required to find the appropriate tool and to await responses.⁸

The numerical rating scale (asking patients to rank pain on a scale of 1-10) and the visual analog scales (a 100 mm line on which the patient is asked to mark the level of pain, from none to severe, with a pencil) are not recommended for use in patients with cognitive impairment. The numerical rating scale was not able to be completed by 1/3 - 1/2 of nursing home patients in three separate studies. The VAS (visual analog scale) was the most difficult to use in a study of community dwelling elders and only 44% of cognitively impaired nursing home residents could complete the scale.¹⁰

MGH Cares About Pain Relief

Massachusetts General Hospital • Founders 606 • 55 Fruit Street • Boston, MA 02114
617-726-0746 (Phone) • 617-724-8693 (Fax) • PainRelief@Partners.org • <http://www.MassGeneral.org/PainRelief>

To be added to or removed from the *Pain Relief Connection* mailing list, send an email to PainRelief@Partners.org

The [Wong-Baker FACES Pain Rating Scale](#), a 0-10 scale of 6 faces with range of smiling to crying, has been found to be an effective measure of pain in children and cognitively intact elders.¹¹ However, in patients with moderate to severe dementia, only 55% of patients with an MMSE of <19, and 41% for those with MMSE < 11 could complete the scale.¹² Another author feels that the FACES scale may be a measure of depression rather than of pain for those with dementia. It is very difficult for patients who lack abstraction skills to reliably translate a crying face to severe pain instead of to a depressed or sad face.¹³

What about pain intensity assessment in patients with advanced dementia who cannot effectively communicate? As dementia progresses, the patient is dependent on the medical staff to evaluate and treat discomfort through the observation of pain behaviors or facial expressions. The concept of a pain assessment tool for advanced dementia is that discomfort can be observed, even though the patient cannot verbally express it. Patients with advanced dementia cannot voluntarily control their expressions, so observed behaviors are considered external markers of internal states.¹⁴

There are three published scales to document pain intensity in patients with advanced dementia. The first one developed was the Discomfort Scale in Dementia of Alzheimer Type (DS-DAT) by Volicer, et al in 1992.¹⁵ The second published was the Assessment of Discomfort in Dementia (ADD) Protocol by Kovach, 1999¹⁶. These first two assessment tools are useful for clinical research but are very difficult and time consuming to use; thus, are not recommended for use in day-to-day assessment of pain in those with advanced dementia.¹⁷

The Pain Assessment in Advanced Dementia Scale (PAINAD) by Volicer, et al. 2001 was developed in response to the need for an easy to use, valid and reliable pain assessment tool in advanced dementia. The paper describing the development and psychometric properties has been submitted for publication and was shared with me by the authors – Warden and Volicer at the Bedford Veterans Affairs Hospital. The PAINAD was based on the earlier DS-DAT protocol but was simplified with a score of 0-10 for severity of pain making it more easily comparable to other pain scales used at the hospital.

The PAINAD is an observational scale based on 5 items with a scale of 0-2 for each:

1. BREATHING (independent of vocalizations) – normal (0) vs labored (1) vs noisy labored (2) or long periods of Cheyne-Stokes respirations.
2. NEGATIVE VOCALIZATION – none (0) vs occasional moans or muttering (1) vs. repeated troubled calling out or loud moaning or crying (2).
3. FACIAL EXPRESSION – smiling or inexpressive (0) vs sad, frown (1) vs facial grimacing (2).
4. BODY LANGUAGE – relaxed (0) vs tense and pacing (1) vs rigid with fists clenched, or striking out (2).
5. CONSOLABILITY – no need to console (0) vs distracted or reassured (1) vs unable to distract or console (2).

Although studies on the PAINAD are very limited, it is well liked, easy to learn, and it is the only scale available for patients with advanced dementia that lends itself to routine clinical use. It is currently being used in routine clinical care as part of the Bedford VA's pain management policy. Hopefully, there will be more published data out soon on the PAINAD scale and its use.¹⁸

In summary, pain is highly prevalent among elders and those with cognitive impairment. Patients with mild-moderate dementia may need to try more than one assessment tool to find one that they understand. Studies show the best tools to be verbal descriptive scales and the worst to be numerical rating scales and visual analog scales. In advanced dementia, when patients cannot communicate their needs, there is very limited data. The best scale for clinical use at this time is the PAINAD scale, which is still not yet published and has limited data available.

Some additional tips for improved assessment of pain in patients with dementia include:¹⁹

- Ask “yes/no” questions
- Palpate areas while asking questions
- Use simple descriptors (aching, hurting)
- Assess pain associated with movement
- Don't dismiss pain behaviors as “just part of dementia”
- Also consider UTI, constipation, urinary retention, compression fractures
- Ask family about previous pain complaints
- Assess pain in any patient with poor sleep, appetite, change in function or agitated behavior

MGH Cares About Pain Relief

Massachusetts General Hospital • Founders 606 • 55 Fruit Street • Boston, MA 02114
617-726-0746 (Phone) • 617-724-8693 (Fax) • PainRelief@Partners.org • <http://www.MassGeneral.org/PainRelief>

To be added to or removed from the *Pain Relief Connection* mailing list, send an email to PainRelief@Partners.org

Links

Mini-Mental State examination: <http://www.minimental.com>

Wong-Baker FACES Pain Rating Scale: <http://www.us.elsevierhealth.com/WOW/faces.html>

Feldt article (Reference #10 & 19, below): <http://www.mmhc.com/nhm/articles/NHM0009/feldt.html>

References

- ¹ McCaffery M. (1968) *Nursing practice theories related to cognition, bodily pain, and man-environment interactions*. Los Angeles: UCLA Students Store. Also: McCaffery M, Pasero C (1999). *Pain: Clinical Manual* (2nd Ed.) St. Louis: Mosby.
- ² Pahor M. Lower body osteoarticular pain and dose of analgesic medications in older disabled women: The Women's Health and Aging Study. *American Journal of Public Health*. June 1999, Vol. 89, No.6, pp. 930- 934;
Sengstaken EA, King SA. The problems of pain and its detection among geriatric nursing home patients. *Journal of the American Geriatrics Society*, 1993. 41(5): 541-544;
Ferrell BA, Ferrell BR, Rivera L. Pain in cognitively impaired nursing home patients. *Journal of Pain and Symptom Management*, Nov 1995. 10(8): 591-598.
- ³ Feldt K. Treatment of pain in cognitively impaired compared with cognitively intact older patients with hip-fracture." *Journal of the American Geriatrics Society*, 1998. 46(9): 1079-1085;
Duggleby, MN. Cognitive status and postoperative pain in older adults. *Journal of Pain and Symptom Management*, Jan 1994. 9(1): 19-27.
- ⁴ Parmelee P. Pain complaints and cognitive status among elderly institution residents. *Journal of the American Geriatrics Society*, May 1993. 41(5): 517-522.
- ⁵ Folstein MF, Folstein SE, McHugh PR. "Mini-mental state." A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, Nov 1975. 12(3):189-98
- ⁶ Wynne C. "Comparison of pain assessment instruments in cognitively intact and cognitively impaired nursing home residents." *Geriatric Nursing*, Jan-Feb 2000. 21(1): 20-23,
- ⁷ Farrell MJ, Gibson SJ, Helme RD. Measuring the activity of older people with chronic pain. *Clinical Journal of Pain*, 1996. 12(1): 6-12
- ⁸ Ferrell BA, Ferrell BR, Rivera L. Pain in cognitively impaired nursing home patients" *Journal of Pain and Symptom Management*, Nov 1995. 10(8): 591-598.
- ⁹ Krulewicz H. Assessment of pain in cognitively impaired older adults: A comparison of pain assessment tools and their use by nonprofessional caregivers. *Journal of the American Geriatrics Society*. 2000. 48: 1607-1611;
Feldt K. Treatment of pain in cognitively impaired compared with cognitively intact older patients with hip fractures. *Journal of the American Geriatrics Society*. 1998. 46(9): 1079-1085;
Herr, K. Comparison of selected pain assessment tools for use with the elderly. *Applied Nursing Research*, Feb 1993. 6(1): 39-46.
- ¹⁰ Feldt K. Improving assessment and treatment of pain in cognitively impaired nursing home residents." *Annals of Long Term Care: Clinical Care and Aging* 2000 (online). 8(9): 36-42;
Herr K. Comparison of selected pain assessment tools for use with the elderly. *Applied Nursing Research*, Feb 1993. 6(1): 39-46;
Wynne CF. Comparison of pain assessment instruments in cognitively intact and impaired nursing home residents. *Geriatric Nursing*, Jan-Feb 2000. 21(1):20-23;
Ferrell BA, Ferrell BR, Rivera L. Pain in cognitively impaired nursing home patients. *Journal of Pain and Symptom Management* Nov 1995. 10(8): 591-598.
- ¹¹ Robertson J. Pediatric pain assessment: validation of a multidimensional tool. *Pediatric Nursing*, 1993. 19:209-13.

MGH Cares About Pain Relief

Massachusetts General Hospital • Founders 606 • 55 Fruit Street • Boston, MA 02114
617-726-0746 (Phone) • 617-724-8693 (Fax) • PainRelief@Partners.org • <http://www.MassGeneral.org/PainRelief>

To be added to or removed from the *Pain Relief Connection* mailing list, send an email to PainRelief@Partners.org

-
- ¹² Krulewitch H. Assessment of pain in cognitively impaired older adults: A comparison of pain assessment tools and their use by nonprofessional caregivers. *Journal of the American Geriatrics Society*. 2000. 48: 1607-1611.
- ¹³ Wynne CF. Comparison of pain assessment instruments in cognitively intact and impaired nursing home residents. *Geriatric Nursing*. 21(1):20-23, 2000 Jan-Feb
- ¹⁴ Hurley AC, Volicer BJ, Hanrahan PA, Houde S, Volicer L. Assessment of discomfort in advanced Alzheimer patients. *Research in Nursing and Health*, 1992. 15, 369-377.
- ¹⁵ Hurley AC, Volicer BJ, Hanrahan PA, Houde S, Volicer L. Assessment of discomfort in advanced Alzheimer patients. *Research in Nursing and Health*, 1992. 15, 369-377.
- ¹⁶ Kovach C. Assessment and treatment of discomfort for people with late-stage dementia. *Journal of Pain and Symptom Management*. Vol 18, No.6, Dec 1999. Pp. 412-419
- ¹⁷ Hurley AC, Volicer L. Evaluation of pain in cognitively impaired individuals. *Journal of the American Geriatrics Society*, Oct 2001. 49(10): 1397-1398
- ¹⁸ Corresponding authors: Warden V & Volicer L, GRECC 182B, EN Rogers Memorial Veterans Hospital, 200 Springs Road, Bedford, MA 01730
- ¹⁹ Feldt KS. Improving assessment and treatment of pain in cognitively impaired nursing home residents. [*Annals of Long Term Care: Clinical Care and Aging*](#) 2000 (online). 8(9): 36-42.

MGH Cares About Pain Relief

Massachusetts General Hospital • Founders 606 • 55 Fruit Street • Boston, MA 02114
617-726-0746 (Phone) • 617-724-8693 (Fax) • PainRelief@Partners.org • <http://www.MassGeneral.org/PainRelief>

To be added to or removed from the *Pain Relief Connection* mailing list, send an email to PainRelief@Partners.org