



Hospice of the Twin Cities

Hospice Insights

Volume 105

July 2006

*“Our greatest glory is
not in never failing,
but in rising up every
time we fail.”*
-Ralph Waldo
Emerson

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A Review of **The Principles of Assessing the Pain of Patients with Dementia** (Ailsa KR Cook, BSc. *Geriatrics & Aging; Volume 4, Number 10, December 2001, 15-16*)

There are many considerations to be made when caring for someone with dementia and pain is one of the most important. When someone with dementia is in pain it may lead to cognitive and behavioral symptoms, intensifying the existing cognitive impairment.

Even with this knowledge research shows that individuals with dementia experience untreated pain. Research also tells us that approximately 25% of cancer patients living in long-term care facilities have untreated pain and there are a disproportionate number within this statistic that have dementia. Research also shows us that long-term care residents with dementia are prescribed pain medications less often than those who do not exhibit signs of dementia. The only way these research results will change, and care will improve, is if professional staff working in long-term care make a greater effort to assess pain on a regular basis for those with dementia.

There are many reasons why pain is not addressed

in this population. One of the main reasons is people with dementia do not usually report their pain. Under-reporting of pain is not unusual in this population's age but is even more prevalent in those with dementia. And sadly, other research shows elderly people who do talk about their pain are not taken seriously and are consequently under-treated for pain. Another reason there is under-reporting of pain in people with dementia is that to spontaneously report pain the person must be aware of the sensation, understand that it can be treated and know that when they report the pain there are health care professionals who can actually treat them for the pain. Because people with dementia have impairment in abstract thinking, reasoning, and memory, all critical ingredients in order to follow the process needed to report pain, there is a huge under-reporting of pain in this population¹.

If pain management is going to improve in this population it is the health-care professional's respon-

sibility to do something about it, not the dementia patients' responsibility². However, research also shows healthcare professionals have a difficult time communicating with people with dementia, another barrier to effective pain management for this population^{3,4,5}. However, there is good news regarding this whole issue and that is that communication can improve leading to improvement in assessment of pain and other undesirable symptoms through the use of a "person-centered" approach⁶.

Person-centered care refers to care that is individualized in its approach to dementia care and recognizes there are many other factors beyond the neuro-anatomy of the dementia that will influence the disease⁷. A recent study found that when dementia clients were asked in an informal, patient-led and person-centered way, 90% of the sample could report pain. To elicit such a high percentage of pain reporting the re-

searcher used the following protocol:

- ◆ Conduct the interview in a quiet and familiar setting.
- ◆ Ensure appropriate sensory aids are in place.
- ◆ Ask people who know the patient well for advice about how best to approach the patient and about their particular communicative difficulties.
- ◆ Ask about pain using words from the patient's vocabulary.
- ◆ Use non-verbal communication to reinforce the message (e.g. making a pained face, pointing to parts of the body that might be sore).
- ◆ Rephrase the questions about pain if the patient could not be made to understand the first time.

Using these methods enabled every patient, who was able to engage with the researcher, make a report of pain.

Research has also shown that pain is more successfully managed when it is assessed and monitored using "formal assessments"⁸⁹. Although using formal assessment tools are preferable, it may be more difficult when dealing with dementia patients because of the cognitive deficit they have. Research finds people with these cognitive deficits have difficulty quantifying pain¹⁰ and only 20% of nursing home residents with dementia were not able to use any of the available tools for pain assessment¹¹. In one research project it was found that two-thirds of

patients with dementia could use at least one of four pain assessment measures. The tool most often used successfully was the McGill Present Pain Intensity Scale: ("Please look at this scale and identify the word or number that describes how bad your pain is at the moment") 0 = No pain; 1 = Mild pain; 2 = Discomforting pain; 3 = Distressing pain; 4 = Horrible pain; and 5 = Excruciating pain.(p.3)

"The findings of this particular research establishes there are certain principles that should be considered when assessing pain in patients with dementia:

- ◆ Assume your patient's pain experience is similar to that of other patients with the same medical condition;
- ◆ Do not assume your patient will make an unsolicited report of pain;
- ◆ Ask your patient, in an informal, person-centered way, if they are experiencing pain and trust that report;
- ◆ If you are unable to elicit a report try asking in a different way or get someone who knows the patient well to ask on your behalf; and
- ◆ Use formal pain assessment tools where possible and be ready to try a number of different tools before you find one that makes sense to the patient." (p.3)

Because pain is a serious threat to a dementia patient's well being,

which includes their functional status and their quality of life, it is imperative that healthcare professionals make the added effort to institute formal assessment techniques when trying to elicit an accurate report of pain from the client with dementia. It is also important to remember there is a small percentage of dementia patients who cannot accurately report pain, or the absence of pain, due to their cognitive status. In those cases it is necessary for the health-care professional to use their skills in recognizing the non-verbal signs of pain and treating it accordingly.

¹Jacques A and Jackson, G. Under standing Dementia. Third Edition. Edinburgh: Churchill Livingstone, 2000.

²Cook AKR, Niven CA, Downs MG. Int J Geriatric Psychiatry 1999; 14:421-5.

³Hellner BM, Norberg A. Int J Aging Hum Dev 1994;38:327-38.

⁴Killick J, Allan K. Milton Keynes: Open University Press, 2001.

⁵Kitwood T. Dementia Reconsidered. Milton Keynes: Open University Press, 1997

⁶Bourgeois MS. J Speech Hear Res 1991;34:831-44.

⁷Kitwood T. Dementia Reconsidered. Milton Keynes: Open University Press, 1997.

⁸Faries JE, Mills DS, Goldsmith KW, Phillips KD, Orr J. Cancer Nursing 1991;14:306-13.

⁹Simons W, Malabar R. J Adv Nurs 1995;22:663-9.

¹⁰Miller J,k Moore K, Scofield A, et al. Orthopaedic Nursing 1996; 15:27-34.

¹¹Ferrell BA, Ferrell BR, Rivera L. J Pain Symptom Manage 1995; 10:591-8.



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Mission Statement

Hospice of the Twin Cities' mission is to enhance the quality of the lives of our patients and their families by providing respectful care based on maintaining dignity, alleviating physical, psychosocial, and spiritual suffering, advocating for fundamental rights, and affirming the sacred value of life.