PATCH program
Home palliative care
End stage dementia—pain assessment and treatment
7/16/07

It is suggested that dementia may be the fourth leading cause of death. And, many more die with dementia as a secondary diagnosis. While patients with dementia do experience pain and other unpleasant sensations, their brain damage causes difficulty in localizing the discomfort, understanding the meaning of it and communicating the discomfort to others. Therefore, there are special challenges to excellent palliative care for the patient dying with dementia.

1. Assessing pain—
    a. Most people with dementia also have co-existing painful conditions.
    b. It may be difficult to elicit details or to remember past pain,
    c. However, many patients (even w/ advanced dementia) can report present pain.
    d. Consider if the patient has conditions which are likely painful
        i. Eg, rotten teeth, active joint effusions, pressure ulcers or contractures
    e. Turn to caregivers who know nuances of patient behavior—they are likely to be able to discern if the patient is in pain.
    f. Patient may express pain or discomfort non-verbally
        i. Eg, wincing, grimacing, crying, groaning, restlessness or irritability
        ii. May express discomfort by refusing food or withdrawing
        iii. Non-verbal pain assessment scales available
    g. Other unpleasant non-pain sensations
        i. Cold, hot, wet, hungry, constipated, lonely, need to be re-adjusted in bed.
        ii. The environment may be loud or confusing.
2. Treating pain
    a. Consider environment
        i. A comfortable, calm, supportive environment helps relaxation.
    b. Cautiously but treat!
       Start low, go slow. Patients with dementia may be more prone to delirium from meds but may also be delirious because of pain.
3. Advance planning
    a. Consider benefits/burdens of diagnostics and treatments
        i. Tests or treatments may cause more harm (especially in a patient who is unable to understand what is happening) or pain than any potential benefit.
    b. Educate family about disease,
        i. If there are advance directives completed, discuss realistic end of life events, eg—infection which might be a comfortable way to die and the options of therapies such as hospitalization and antibiotics.

ii. While it is difficult to predict six month life expectancy in end stage dementia, hospices usually are happy to enroll.
iii. Tube feeding conversation/stats—Several studies fail to show decrease in aspiration or weight loss or increase in survival.

4. Nutrition
    a. Hand feeding associated with pleasure of eating including experiencing taste and texture and having someone touch and attend.
    b. Weight loss is usual

Bibliography

Volicer, L. Management of severe Alzheimer's disease and end-of-life issues. Clinics in Geriatric Medicine 17:2. 2001

Finucane TE, Christmas C, Travis K: Tube feeding in patients with advanced dementia: A review of the evidence. JAMA 282:1365-1370, 1999

Fried TR, Gillick MR, Lipsitz LA: Short-term functional outcomes of long-term care residents with pneumonia treated with and without hospital transfer. J Am Geriatr Soc 45:302-306, 1997

Hanrahan P, Luchins DJ: Access to hospice programs in end-stage dementia: A national survey of hospice programs. J Am Geriatr Soc 43:56-59, 1995

Hurley AC, Volicer BJ, Hanrahan P, et al: Assessment of discomfort in advanced Alzheimer patients. Res Nurs Health 15:369-377, 1992

Luchins DJ, Hanrahan P, Murphy K: Criteria for enrolling dementia patients in hospice. J Am Geriatr Soc 45:1054-1059, 1997

Merriam AE, Aronson MK, Gaston P, et al: The psychiatric symptoms of Alzheimer's disease. J Am Geriatr Soc 36:7-12, 1988

Morrison RS, Ahronheim JC, Morrison GR, et al: Pain and discomfort associated with common hospital procedures and experiences. J Pain Symptom Manage 15:91-101, 1998

Rheaume Y, Riley ME, Volicer L: Meeting nutritional needs of Alzheimer patients who pace constantly. J Nutr Elderly 7:43-52, 1987

Volicer BJ, Hurley A, Fabiszewski KJ, et al: Predicting short-term survival for patients with advanced Alzheimer's disease. J Am Geriatr Soc 41:535-540, 1993

Shuster JL. Death and dying: Palliative care for advanced dementia. Clinics in Geriatric Medicine. 2000:16(2)