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—infeciton 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


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