Caring for the Patient with End-Stage Dementia

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DEMENTIA

- Exceedingly common among the elderly
- Alzheimer’s Disease – 6th leading cause of death
- Most dementias irreversible
- Median survival- 5 years from diagnosis
- Given above facts dementia must be considered a terminal illness YET:
Ample evidence patients with end-stage dementia receive sub-optimal end-of-life care and other experience unrelieved suffering.

In a 2005 study two-thirds of Nursing Home (NH) residents with dementia did not receive hospice care.
CONSEQUENCES

- Unrelieved suffering for patient and family
- Complicated grief for family
- Families appreciate hospice care
- Greatest barrier: PROGNOSTICATION
PROGNOSTICATION

• Difficult to predict 6-month mortality
• Behavior problems in dementia are unfamiliar to hospice staff.
• Most lay people find it difficult to view dementia as a terminal illness.
• True trajectory of end-stage dementia is not steady decline but instead recurrent health crises and hospitalizations.
PROGNOSTICATION PREDICTORS

- Severity of dementia at initial diagnosis
- Rate of cognitive deterioration during first year after diagnosis
- Male gender
- Falls/Gait disturbance
- Diabetes; Congestive heart failure
- Most ominous: pneumonia, fever, hip fracture
CARE PLANNING STRATEGIES

- Early education, patient and family is essential.
- Important scenarios, such as tube feeding and do-not-hospitalize orders are rarely addressed.
- Explore “do everything possible” with family.
- Steer toward honoring patient’s wishes and NOT inflicting meaningless suffering.
ADDRESSING COMPLICATIONS OF END-STAGE DEMENTIA

- Behavioral problems
- Sleep disturbances
- Delirium
- Pain
- ANOREXIA and CACHEXIA
- Other symptoms
- Treating intercurrent illnesses
BEHAVIORAL PROBLEMS

- More prominent in advanced dementia
- Agitation is a sign of patient distress
- Broad differential diagnosis; acute v chronic
- Resistance to hands on care is common
- Ideally management is non-pharmacologic
- Antipsychotics are most effective option, with caveats.
- Depression is also common
**SLEEP DISTURBANCES**

- Sleep worsens as dementia progresses as normal diurnal rhythms disintegrate.
- Shift environment, not patient
- Sleep hygiene helpful
- Hypnotics may improve quality of life
DELIRIUM

- Dementia is a strong predictor of delirium
- Delirium: acute onset, fluctuating course, decreased attention, and altered consciousness
- Agitated delirium is distressing to patients and frightening to caregivers
- Antipsychotics are treatment of choice
- Avoid excessive hardware
PAIN

- Self-report is lost
- High index of suspicion and multiple ‘expressions’ of pain
- Patients with dementia receive less analgesics
- Use scheduled, not PRN analgesics
- Begin with Acetaminophen
- Beware of constipation with opioids
ANOREXIA AND CACHEXIA

• Preterminal markers to end-stage dementia
• Unresponsive to artificial nutrition
• Tube feeding is without benefit; it increases ER visits, hospitalizations, and suffering
• Risks/burdens of tube feeding, lack of evidence, and other options are rarely discussed
• Optimize oral feeding
OTHER SYMPTOMS

- Seizures - late in course (20%), brief, easily controlled
- Dyspnea - associated with weakness/pneumonia
- Constipation - common secondary to poor hydration, inactivity, and medications
- Pressure ulcers - prevent pain not promote healing
TREATING INTERCURRENT ILLNESSES

- Goals: patient’s life expectancy, quality of life, family’s wishes
- Choices: recovery, symptom management, or noninvasive approach
- Medication administration - challenging
- Recurrent pneumonia is most common cause of death
- Urinary Tract Infections (UTIs) - common; often overtreated
- Consider “Do Not Hospitalize” orders
HELPING WITH BEREAVEMENT

• Dementia is a relentless attack on identity
• Family experiences numerous “small” deaths
• Much grieving done before actual death
• Dementia leads to major role changes
• Often conflict about advance directives
• Help families early
• Be vigilant for complicated grief
CONCLUSION

• When cure is not possible focus on what is possible: relieve suffering

• With forethought and compassion patients with end-stage dementia may die with peace and dignity leaving positive memories.