

Hospice and Palliative Care Alzheimer's Disease Working Group July 9, 2015

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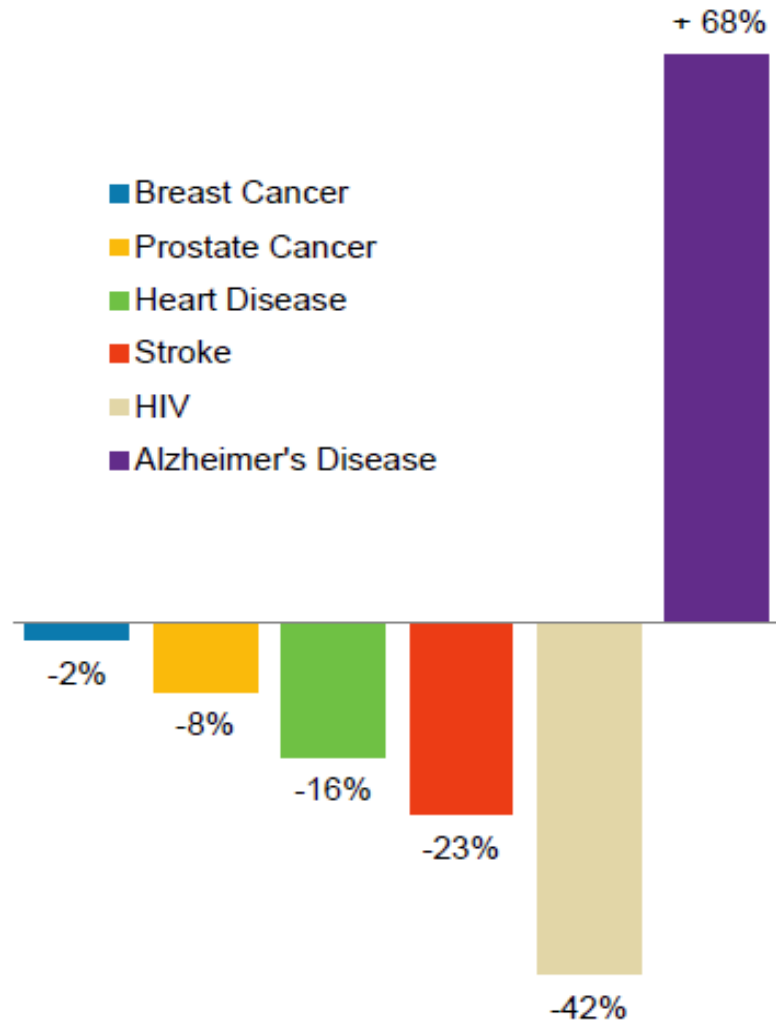
Palliative Care

- Specialized medical care for person with serious illness. Focused on providing patients with relief from the symptoms, pain, and stress of a serious illness-whatever the diagnosis. The goal is to improve quality of life for both the patient and the family
- Palliative care is provided by a team of doctors, nurses, and other specialist together with a patient's other doctors to provide an extra layer of support, appropriate at any age and at any stage in a serious illness and can be given with curative treatment.

Hospice Care

- Specialized care for persons and families with terminal illness and life expectancy of 6 months or less
- Provided by interdisciplinary team
- Focused on whole person care and quality of life
- Provided in homes, facilities, or specialized hospice units
- Medicare benefit –paid on per diem rate

Change in Number of Deaths Between 2000 and 2010



Integrated Palliative Care Framework



NHWG. Adapted from work of the Canadian Palliative Care Association and Frank Ferris, MD.

Referral to palliative care based on unmet need
Referral to hospice based on prognosis

AMA Quality Dementia Measure

American Academy of Neurology 2013
Neurology 81 October 22, 2013

1. Staging of dementia
2. Cognitive assessment
3. Functional status assessment
4. Neuropsychiatric symptom assessment
5. Management of neuropsychiatric symptoms
6. Screening for depressive symptoms
7. Counseling regarding safety concerns
8. Counseling regarding risks of driving
9. Palliative care counseling and advance care planning
10. Caregiver education and support

Elements of Palliative Care in Patients with Dementia

Element

Communicating the diagnosis
Communicating prognosis
Helping patient and family with anticipatory grief
Assessing decisional capacity
Helping patient assign a surrogate decision maker
Discussing goals of care
Discussing the role of artificial nutrition
Discussing the role of antibiotics
Helping patient and surrogate complete advance directives
Planning for transitions in living situation if necessary
Assessing medication appropriateness
Assessing for comorbid depression
Assessing and treating pain
Assessing and treating delirium
Reassessing goals of care and appropriateness of hospital transfer
Making hospice referral when appropriate
Managing terminal pain and delirium
Responding to family's grief after patient death
Expressing condolences
Referring to community resources for grief counseling

Stage of dementia



Barriers to Palliative Care for Persons with Dementia

- Dementia is not considered a terminal illness
- Lack of clinical knowledge about the course of dementia
- Lack of time to address in clinical visits
- Lack of reimbursement to discuss advance care planning
- Primary care considered the “owner” of advance directives
- Lack of coordination among clinicians, medical organizations (EMR)
- Change of goals as illness changes

Access to Hospice Care

- Utilization of hospice low for persons with dementia
- Estimate of 18-22% of all person dying with dementia receive hospice care
- Virtually all hospices provide care for persons with dementia
- Need is to manage the high symptom burden of pain, agitation and shortness of breath.

Barriers to Hospice Care

- Little research that looks at palliative or hospice care for person with dementia
- Dementia not viewed as terminal illness
- Lack of knowledge
- Difficulty in prognostication

Initiatives to Improve Access

- Educational efforts
- Collaborative efforts
- Teaching Rounds with gero-psychiatrist
- Franciscan Palliative Care Academy

Questions?