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Suffering in Silence: Improving Care for Persons With Dementia

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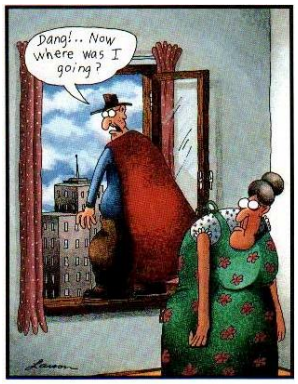
- The needs of an aging society
- Sources of suffering in advanced dementia
- The challenges of improving care
- Summary and discussion

The Case of A.S.

A.S. was an 85 year old woman with advanced dementia who was admitted to Mount Sinai Hospital in 3/94 from a personal care home with urosepsis. She had no known family and had been living in the nursing home for approximately 5 years. On admission, she was extremely agitated and combative. Over the next 48 hours, she responded well to antibiotic treatment but her behaviour became more disruptive. She displayed marked sleep wake cycle disturbances, resisted all attempts to transfer or reposition her, refused to eat, and was treated with escalating doses of haloperidol and physical restraints. On hospital day 3, a geriatric consultation was called to assist with the management of her "behavioural disorder".

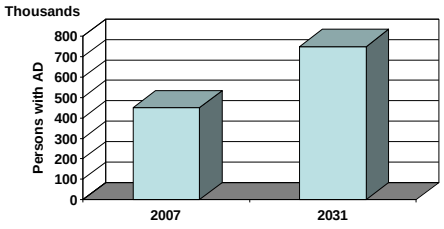
The Case of A.S.

On exam the geriatric consult team noted a large 4 by 5 cm left breast mass. Palpation of her ribs and shoulders elicited withdrawal and groaning. A.S. was started on intravenous morphine sulfate. With escalating doses of morphine, her agitation resolved, as did her sleep wake cycle disturbance, her anorexia, and her resistance to movement. Major tranquilizers and physical restraints were discontinued. Skeletal survey revealed widespread bone metastases. She was discharged to the personal care home with hospice on oral morphine sulfate.



Superman in his later years

Prevalence of Alzheimer's Disease in Canadians Over Age 65



Canadian Study on Health & Aging

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Alzheimers & Related Dementias

- Affects 30-40% of patients over 85 (50% in advanced stages)
- Two thirds of newly admitted personal care residents have a diagnoses dementia
- Currently costs 37,000 per year in caregiver, nursing home, and medication costs (5.5 billion dollars per year)
- Projected 750,000 Canadians will suffer from advanced dementia by 2030
- There is no cure and disease modifying therapies are only marginally effective

Survival Time Among Hospice Patients With Dementia

- Prospective study of 47 patients enrolled in hospice (dependent in ADL's with limited speech)
  - Median survival of 4 months
  - 38% survived beyond 6 months
  - Of those who survived more than 6 months, mean survival was 16 months.

Luchins and Hanrahan JAGS, 1997.

- National Medicare Database
  - Median survival of 2.5 months
  - 35% survived beyond 6 months

Christakis and Escqarce, NEJM, 1996

Palliative Management of Fever in Nursing Home Residents With Advanced Dementia

- 104 patients with advanced dementia and fever who received either "palliative care" or "routine" medical management that included fever work up and antibiotics in the nursing home
- Antibiotic treatment had no effect on 6 month mortality
- Patients assigned to "routine" care were less likely to receive analgesics (14%) than those who received palliative care (40%)
- "Routine" care was associated with higher costs and greater discomfort as rated by nurses

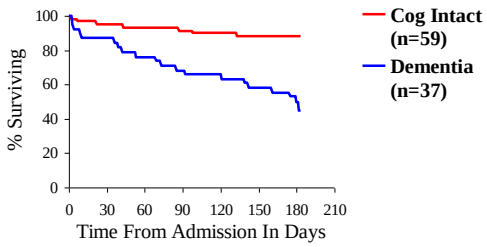
Fabiszewski et al, JAMA 1990

Survival in End-stage Dementia Following Acute Illness

- Prospective cohort study of cognitively intact and end-stage dementia patients hospitalized with pneumonia (n=119) or hip fracture (n=97)
- All pneumonia subjects received antibiotics
- All but 3 hip fracture subjects received operative repair
- Life prolonging therapies withdrawn in 8 subjects (6 with dementia)
  - Decision made only when death was imminent

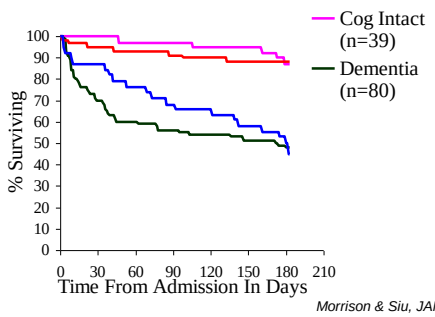
Morrison & Siu, JAMA, 2000

Survival Following Admission For Hip Fracture



Morrison & Siu, JAMA, 2000

Survival Following Admission For Pneumonia



Morrison & Siu, JAMA, 2000

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The Burden of Dementia...

- Financial and emotional costs to families and family caregivers
  - >90% have a family caregiver (>70% are women)
  - 20-40% of caregivers report depression
  - Caregivers reporting strain have a 1.5 fold increased risk of death
- Decades of progressive dependency
- Loss of work, family network, social supports, health, and savings.
- Untreated physical symptoms

Sources of Suffering in Advanced Dementia - Pain

- More than 80% of cancer patients experience moderate to severe pain prior to death
- Over two thirds of patients dying of diseases other than cancer experience moderate to severe pain prior to death
- 40-60% of older adults report persistent daily pain
- Fifty percent of these patients receive inadequate analgesia for their level of pain
- What percentage of end-stage dementia patients experience pain and how well is it treated?

Is Pain Different in Dementia?

- Tolerance to *acute* pain *possibly* increases but pain threshold does not appear to change (Benedetti et al, 1999;2004)
- Dementia may blunt autonomic nervous system's response to acute pain (Rainero et al, 2000)
- Cognitive impairment *may* decrease perceived analgesic effectiveness (Benedetti et al, 2006)
- **No** evidence that dementia results in the loss of the ability to feel pain

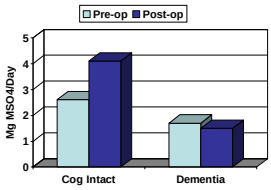
Undertreatment of Pain in Hospitalized Patients With Advanced Dementia

- Prospective cohort study of 59 cognitively intact elderly patients with hip fracture and 38 patients with hip fracture and advanced dementia
- Daily rating of pain by cognitively intact patients
- Comparison of analgesic prescribing practices

Morrison & Siu, JPSM, 2000

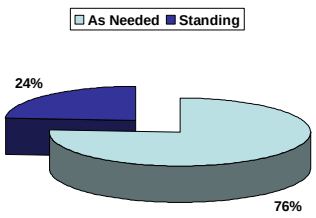
Analgesic Prescribing in Hip Fracture Patients with Advanced Dementia

- 76% of cog. intact patients rated their average pre-operative pain as moderate-severe
- 68% of cog. intact patients rated their average post-operative pain as moderate to severe



Morrison & Siu, JPSM, 2000

Analgesic Prescribing For Dementia Patients Following Hip Fracture Repair



Morrison & Siu, JPSM, 2000

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Undertreatment of Pain in Nursing Home Residents With Dementia

- Pain is documented less frequently for dementia residents, even with similar numbers of painful diagnoses as less impaired residents (Sengstaken & King, 1993)
- Less analgesic is prescribed/administered for dementia residents, despite similar numbers of painful diagnoses (Horgas & Tsai, 1998)
- Only ¼ of demented residents who are identified as having pain receive any analgesic therapy (Scherder et al, 1999; Bernabei et al, 1998; Won et al, 1999)

Pain, Opioids, and Delirium

Suffering in silence: Inadequate treatment of pain.....

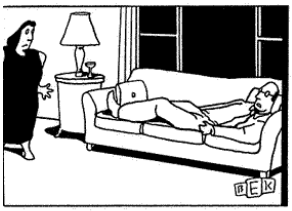
Authors: Morrison & Siu.

- The authors are correct in pointing out that hospitalized elderly and demented patients in pain are under treated in terms of narcotic analgesic medication use. This is not due to an act of omission or an assumption that these patients do not suffer pain. Most mature clinicians know from experience that aggressive use of narcotic analgesics can be a potent cause for precipitating delirium in these patients.
- The study findings restate what is already a matter of intent for most clinicians.
- This study does not add much to our existing body of knowledge.

-An Anonymous Reviewer, Ann Intern Med

Delirium

- **Incidence & Costs**
  - 7% - 10% of all persons over age 65 years develop delirium annually
  - Complicates hospital stay for > 2.2 million persons/year
  - Estimated costs: > $8 billion/year
- **Outcomes:**
  - ↑ LOS
  - ↑ Complication rate
  - ↑ Mortality
  - ↑ D/C to SNF
  - ↑ Cognitive decline
  - ↑ Risk major depression
  - ↑ Loss of ADLs
  - ↓Functional recovery



"My back is fine. My mind went out."

Pain, Opioids, and Delirium

- Two studies* have reported a significant association between opioid use and delirium
  - Neither study controlled for pain
  - All patients received meperidine
- Five studies† have reported a significant association between uncontrolled pain and delirium
  - No relationship found between opioid use/dose and delirium in 4 studies
  - Opioids found to reduce the risk of delirium in 2 studies

**Marcontonio et al, JAMA 1994, Schor et al, JAMA 1992*

†Egbert et al, Arch Intern Med 1990 ,Duggleby & Lander, JPSM 1994, Lynch et al, Anesth Analg 1998; Morrison et al, J of Gerontology: Medical Sciences, 2004;xxx

Risk Factors For Delirium in Hip Fracture Patients

- Subjects able to self-report pain
  - Severe pain prior to delirium
    - OR 9.0, 95% CI 1.8-45, P=0.01
  - Low doses of opioids (<10 mg of parenteral milligrams of mso4/day)
    - OR 4.4, 95% CI 0.3-68.6, P=0.03
  - Received meperidine (NS)
  - Increase in opioid dose after pain detected (NS)
- Subjects unable to self-report pain
  - Low doses of opioids (<10 mg of parenteral milligrams of mso4/day)
    - OR 4.0, 95% 1.6-10.2, P=0.004
  - Received meperidine
    - OR 3.4, 95% 1.6-6.9, P=.001

Morrison et al, J Gerontol Med Sci, 2003

Sources of Suffering in End-stage Dementia - Pneumonia

- 39 cognitively intact subjects asked to rate symptoms associated with pneumonia
  - Over 50% experienced at least one episode of severe dyspnea
  - 50% experienced moderate to severe anxiety
  - 40% experienced moderate to severe pain from coughing
  - 20% experienced severe nausea

Morrison & Siu, 2000

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Sources of Suffering in End-stage Dementia – Iatrogenic Interventions

- 165 cognitively intact adults hospitalized with acute medical illness
- Subjects asked to rate pain and discomfort associated with common hospital procedures received by end-stage dementia patients
- Ratings on a 0-10 cm visual analog scale

Morrison et al, JPSM 1998

Pain Ratings For 16 Common Hospital Procedures For 165 Subjects

- **Severe (8-10)**
  - Arterial blood gas
- **Moderate (4-7)**
  - Central line placement
  - Nasogastric tube
  - Peripheral IV insertion
  - Phlebotomy
- **Mild (1-3)**
  - IM/SC injection Urethral catheter
  - Mechanical restraints
  - Movement from bed to chair
- **None (0)**
  - IV catheter
  - Chest x-ray
  - Transfer to a procedure
  - Waiting for a test or procedure
  - PO medications

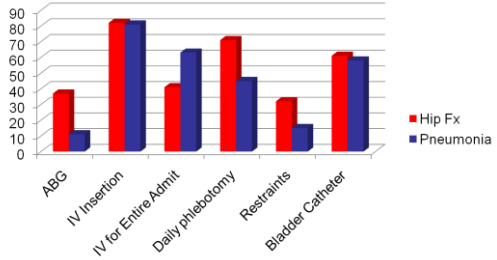
Morrison et al, JPSM 1998

Discomfort Ratings For 16 Common Hospital Procedures For 165 Subjects

- **Severe (8-10)**
  - Nasogastric tube
  - Mechanical ventilation
  - Mechanical restraints
  - Central line placement
- **Moderate (4-7)**
  - Arterial blood gas
  - Urethral catheter
- **Mild (1-3)**
  - IV insertion
  - Phlebotomy
  - IV catheter
  - IM/SC injection
  - Waiting for procedures
  - Movement from bed to chair
  - Chest X-ray
- **None (0)**
  - Transfer to a procedure
  - Vitals signs
  - PO medications

Morrison et al, JPSM 1998

Prevalence of Painful/Uncomfortable Procedures in Hospitalized Dementia Patients



Morrison et al, JAMA 1998

Outcomes of Physical Symptoms Pain

- Unnecessary suffering
- Depression and anxiety
- Impaired ambulation, gait disturbance
- Sleep disturbances
- Decreased socialization
- Increased healthcare utilization
- Increased agitation and resistance to care
- Impaired cognition

Additional Sources of Suffering in Dementia

- Loss of identity and personhood
- Loss of control
- Loss of meaning and purpose
- Burden on loved ones (physical, financial, emotional, spiritual)

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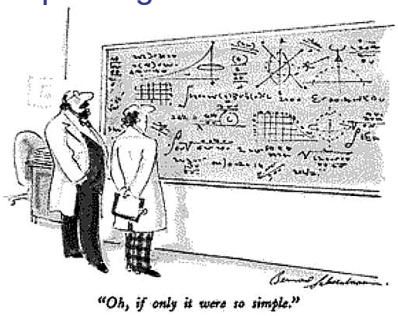
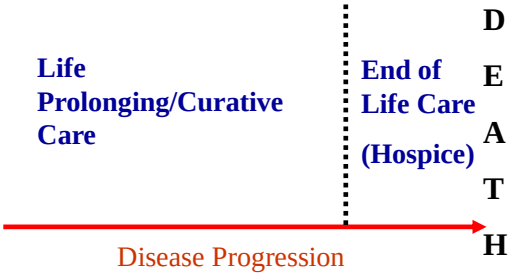
The Challenge of Improving Care



What Palliative Care is Not



I don't want to achieve immortality through my work. I'd rather achieve it by not dying.

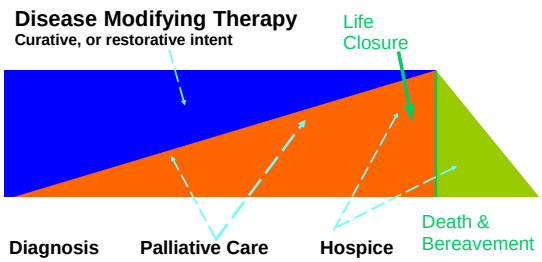
Woody Allen

If we are to truly reach patients and families who need palliative care, we cannot equate it with end-of-life care, care of the dying, or an alternative to aggressive care.

Efforts to Improve Palliative Care in the U.S. (1995-2004)

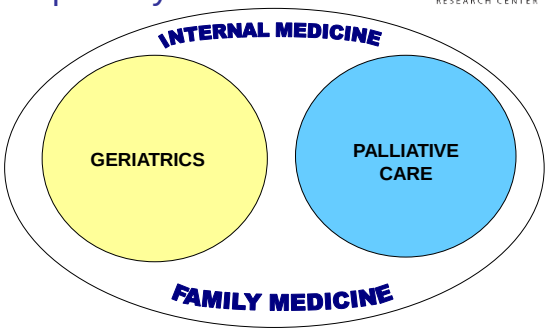
- Project on Death in America
  - *George Soros's initiative to fund palliative care initiatives*
- Promoting Excellence in End-of-Life Care
  - *RWJ initiative to support research/education in palliative care*
- On our own terms: Moyers on Dying
  - *8 hour PBS series on palliative care*
- Last Acts
  - *RWJ consumer advocacy organization*
- Approaching Death: Improving care at the end of life
  - *Institute of Medicine report*
- A Means to a Better End
  - *National report card on palliative care*

A New Vision of Palliative Care



NHWG; Adapted from work of the Canadian Palliative Care Association & Frank Ferris, MD

Specialty Based Care



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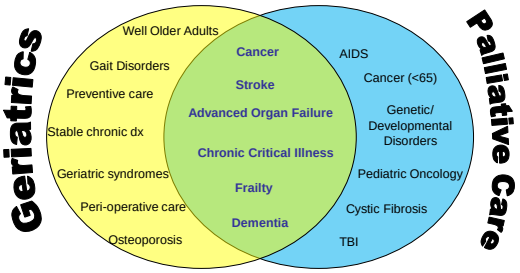
Patient Centered Care

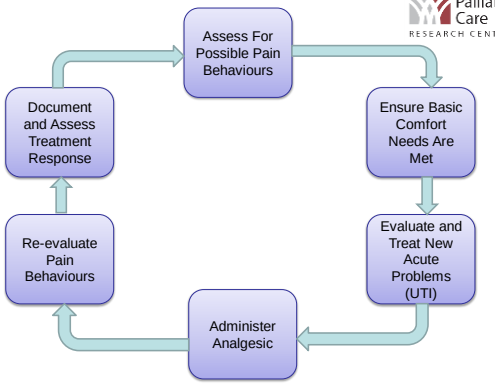


What can we do?

- Integration of life prolonging care with care focused on comfort with a continual re-evaluation as to how to optimize quality of life and meet changing goals of care

Treating Pain in Dementia

- Resident report *(if possible)*
- Prior pain history
- Painful diagnoses
- Behavioral indicators
- Observer assessment
- Response to empirical therapy



Evidence for Attempting Empirical Analgesic Trials

- Regular analgesic therapy increased social engagement in NH residents (Chibnall et al, 2005)
- Use of standardized assessment and treatment protocol significantly decreased discomfort among demented NH residents (Kovach et al, 1999)
- Acetaminophen 650 mg TID APAP: 63% decrease in negative behaviors, 75% psychotropics discontinued (Douzjian et al, 1998)

Potential Goals of Care:

- Cure of disease
- Avoidance of premature death
- Maintenance or improvement in function
- Prolongation of life
- Relief of suffering
- Quality of life
- Staying in control
- Preserving dignity
- Support for families and loved ones
- A peaceful death

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Identifying Goals of Care In Early Stage Disease

- What makes life worth living for you?
- Tell me about a face worse than death?
  - Being dependent in ADLs
  - Being in a personal care home
  - Not being able to recognize family
  - Not being able to communicate with family
- If you were unable to eat normally, would you want have a feeding tube?

Identifying Goals of Care in Late-Stage Disease

- Tell me what made life worth living for [insert name]
- Would [insert name] consider this an acceptable quality of life
- What would [insert name] tell us to do if he/she could?
- What do you understand about tube feeding?

Decision Nodes

- Hospitalization for acute illness
  - Benefits
    - ICU care, intravenous therapies, intensive monitoring
  - Burdens
    - Disorientation, painful iatrogenic interventions, care team unfamiliar with patient, hazards of hospitalization, increased mortality and functional decline (pneumonia)
- Antibiotics for fever
  - Benefits
    - Improved survival in early-mid stage disease, Rapid symptom resolution (UTI)
  - Burdens
    - No improvement in 6 month survival in late-stage disease, Medication side effects
- Artificial nutrition & hydration

The Evidence Base for Tube Feeding in Dementia

- Tube feeding does not prevent aspiration pneumonia
- Tube feeding does not improve survival
- Tube feeding does not result in meaningful weight gain
- All true but…
- There are no randomized controlled trials

Does tube feeding meet the patient's goals?

- End-stage dementia patients who stop eating and drinking do not appear to exhibit signs or symptoms of discomfort
- Subjects patients to an uncomfortable, painful, but relatively low risk procedure (endoscopy)
- Eliminates the attention and human contact that spoon feeding provides
- Eliminates the pleasurable oral sensation of food and drink
- Associated with an increased use of restraints
  - 70% in one study
- Is it consistent with the patients' and families' known wishes for care?

Treatment plans

- Identify chronic conditions associated with known pain or discomfort from medical history/physical exam
  - Osteoarthritis, diabetic neuropathy, COPD
- Pre-emptive analgesia
- Minimize or eliminate painful iatrogenic procedures
- Empiric analgesic treatment trials
- Documented treatment plan for anticipated complications
  - Infection, feeding disorders, stroke
- Informal and formal caregiver support and treatment plan

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Some Final Challenges

- Difficulty in finding meaning and value in caring for non-communicative patients
- Loss of primary care providers that treated patients prior to the onset of their dementia
- Lack of advocates/surrogates for dementia patients
  - 50% of dementia subjects admitted to hospital lacked a functioning surrogate who could consent for medical treatment (Baskin et al, JAGS, 1998)

"It's fine to discover cures, but, remember, chronic conditions are our bread and butter."