GOALS OF CARE

A TOUR OF THE INDIVIDUAL'S LIFE

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LEARNING OBJECTIVES

- To develop an understanding of the meaning of goals of care
- To increase knowledge of how goals of care can be used to develop a care approach
- To develop an understanding about how to re-evaluate goals of care as a person's health status changes

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WHAT ARE GOALS OF CARE?

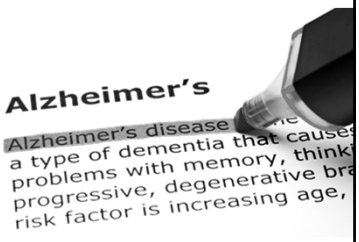
- Goals are simply the ideals we are trying to achieve
- Care is the way we address a concern
- Goals of care change with the health, age, and social situation of a person
- Goals of care are very individualized
- Goals of care often mean different things to different health professionals

DIFFERING CARE GOALS FOR DIFFERENT PERSONS

- 72 year old female with newly diagnosed pancreatic cancer:
  - Physician: Find a treatment that will buy time
  - Nurse: Alleviate physical pain
  - Social Worker: Assist patient and family with coping
  - Family: Cure mom
  - Patient: Live to see grandchild born

Goals Change with Age and Medical Status

- Early Alzheimer's
  - Be able to maintain normal social relations
- Moderate Alzheimer's
  - Be able to care for personal needs
- Severe Alzheimer's
  - Not be a burden on my family



Goals May Diverge with Age

- Most younger persons have similar wishes
  - Long healthy life
  - Healthy children/good social supports
  - Fiscal stability
  - Independence with age
  - An easy death
- Things aren't so easy as we age and approach end of life…

Goals of Care in the Aged: Example 1

- Dr. Robert Weiss, retired physician, former Harvard Medical School professor and dean, School of Public Health at Columbia University, 90 years old, advanced pulmonary hypertension
- "It's not that I want to die. But I've lived a very full life… and it's perfectly legitimate to expect to die. I just would hope to die comfortably."
- Current system motivates practitioners "to squeeze the last inch of life out of people instead of allowing them to die comfortably"
- "Routine, preventive testing should be discontinued once people reach a certain age, as is the policy in many European countries"

Goals of Care in the Aged: Other Examples

- Dr. Michael DeBakey, pioneering heart surgeon, age 97, undergoes aortic dissection repair (after Ethics committee consultation), lives 2 years
- Hazel Homer, 99 year old, congestive heart failure and arrhythmia, receives a combination biventricular pacemaker and defibrillator, cost of $35,000, still alive 5 years later
  - Cardiologist: "You get a lot of criticism for doing this sort of thing. People say it's not cost effective, she's going to die anyway."

Goals Should Change with Time and Condition

- Only 50% of Americans die needing little help
- 40% need assistance with ADL/IADLs for up to 5 years
- 10% need more than 5 years help
- Increasing care needs generally affects goals of care
- Progressive Intermittent Frailty describes the decline many Americans experience

Progressive Intermittent Frailty

- PIF notes most patients have periods of illness and health
- Decline during illness normally not resolved by period of recuperation
- Each illness has associated worsening quality of life as much if not more than quantity of life
- Each illness has worsening chance of survival
- Each episode offers opportunity to reconsider goals of care

Progressive Intermittent Frailty

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So Do We Rewrite Goals with Every Illness?

- The short answer is no
- There are underlying tenets of goals of care that are a part of every care plan
- Within each tenet, the balance of attention will shift with patient changing condition
- These tenets transcend different discipline

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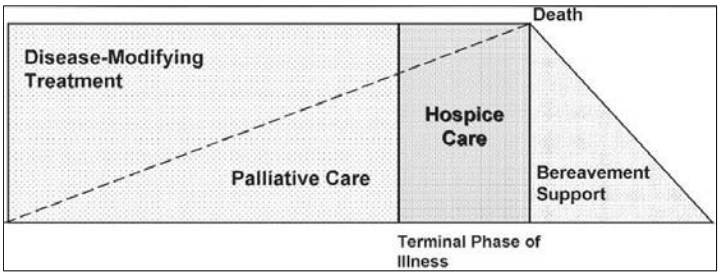
Treatment Model



Adapted from: Mazanec, P, Daly, B. J., Pitorak, E. F., Kane, D., Wile, S. and Wolen, J. (2009). A new model of palliative care for oncology patients with advanced disease. *Journal of Hospice and Palliative Nursing. Retrieved from:* http://www.medscape.com/viewarticle/712742

The Four Basic Tenets of Goals of Care

- Restorative
  - If practical, make me better
- Maintenance
  - If that's not possible, then keep me stable
- Preventative
  - If that's not possible, then slow my rate of decline
- Palliative
  - Throughout all my time with you, let me direct my care and keep me comfortable

Goals of Care A-Team Approach

- Encourage multiple and early discussions
- Involve other health care team members, such as your nurse practitioner or social worker, to continue discussions and reinforce choices
- When possible and appropriate, involve family members in the discussions

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Current Status of EOL Care and Advanced Directives

- AD and EOL considerations are often ignored by health professionals and patients alike, until nature forces it upon them
- Obtaining AD and provision of quality end-of-life care is often overlooked, seldom taught and rarely measured within training programs
- Public education about AD and EOL is abysmal
- Symptom management of terminal patients is often inadequate, promotes overuse of aggressive care
- One-fourth of all Medicare dollars are spent during the last year of life

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Variability in Costs of Care Last Two Years of Life

Institute	Costs
UCLA	$93,284
John Hopkins Hospital	$85,729
Massachusetts General	$78,666
Cleveland Clinic	$55,333
Mayo Clinic	$53,432

Transforming Hospice to Continuous Quality Care at EOL

- People mostly die from statistically describable events, but the individual unpredictable process may take 2 months or 22 months
- Change the current all-or-nothing hospice model to a layered system that accounts for three trajectories toward death
  - after a short period of decline
  - after a sudden exacerbation of illness
  - slow process due to long-term health problems

Joanne Lynn, MD, CMS at AGS Annual Symposium 2008

CARE TYPES

- **Effective care:** evidence-based interventions with demonstrated benefits so far exceeding harms that all patients in need should receive the service; variations reflect a failure to deliver needed care, or underuse
- **Supply-sensitive care:** services where the supply of a specific resource has a major influence on utilization rates; variations are largely due to difference in local capacity, and payment systems that ensures continued existing capacity

CARE TYPES

- **Preference-sensitive care:** treatment decisions where different choices carry different benefits and risks, and where patients' attitudes toward these outcomes vary; unwarranted variations reflect both the scientific evidence limitations and lack of informed patient choice
- **Valued-based care:** services based on policies that promote comparative and evidence care, and information technology and economic incentives; variations based on limits of system and goal misalignment

CARE, QUANTITY AND QUALITY

- Medical hospitalizations, ICU stays, physicians visits, specialists visits, diagnostic tests, HHC and LTC are supply-sensitive care
- Supply-sensitive service per capita use varies remarkably among communities
  - largely independent of patient characteristics and illness, variation in patient preferences for aggressive care or in malpractice risk
- Resource supply and utilization are highly linked
  - more than half of variation in hospitalization and physician services utilization is explained by supply

Dartmouth Atlas of Health

CARE, QUALITY AND QUANTITY

- Well over half of Medicare spending is supply sensitive and coupled with severe chronic illness
- Greater per capita use of supply-sensitive care and more spending do not result in lower mortality or improved QoL or QoC
- Regions and hospitals with high rates of utilization may in fact be over-treating patients. Unnecessary care is not producing better outcomes
- Chances of dying increase in regions where the health care system delivers more care

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CARE TYPES AND AD/EOL

- Preference sensitive care and supply sensitive care has been postulated to be affected by good AD planning and good EOL care
- Financial data indicate AD and EOL do provide value-based care
- Much of basis of AD and EOL is in the concept of "Slow Medicine"

"SLOW MEDICINE"

- Medical care that is deliberately and carefully administered with balanced review of clinical evidence of efficacy and limitations, and individual preferences
- Greater emphasis on evaluation and management (E/M) services and lesser on technologic services
- Diminishes supply-sensitive effect, emphasizes effective, preference and valued based care
- Demands thought, time, energy
- Demands thoughtful AD

My Mother, Your Mother, Dennis McCullough, M.D

Resident Rights Regarding EOL Care and Advanced Directives

- Right to Participate in One's Own Care
  - Be informed of all changes in medical condition
  - Participate in own assessment, care-planning, treatment, and discharge
  - Refuse medication and treatment
- Right to Dignity, Respect, and Freedom
  - To self-determination
- Right to Make Independent Choices
- Right to be Fully Informed of Available Services and Charges for Each Service

Respecting Choices

- Involve patient, family members, and surrogate decision makers in advanced care planning discussions and advanced directives
- Involve an interdisciplinary team of health professionals - social workers, nurses, counselors, psychologists - to work with patients and their families on these matters before a health crisis occurs
- Encourage communication of patient choices to family members and health care providers

Questions?