...the effect of end-of-life transition on individuals, families and society.

Service & Delivery Systems

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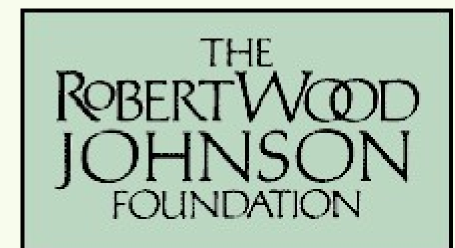
Describe both present practices and future needs of end-of-life care.

Introduction

- Most Americans will need some form EOL professional health care, especially from:
  - Professional clinical services
  - Counseling
  - Practical assistance for both medical and non-medical needs
- Hindering this effort:
  - Limited data about care systems' EOL care services
- End-of-life care is being moved into public view by media and foundations.
  - Robert Wood Johnson Foundation



Settings Where Palliative & End-of-Life Care Takes Place

- Most common setting: **Hospitals**
  - Most dying receive some hospital care
  - Acute care facilities regard death as failure
- Other settings:
  - Nursing home; long term care facilities; their own homes
- Differences among hospitals make it improbable for a single model for end-of-life care.
- Modern care medical facilities regard death as failure:
  - Emphasis on ‘high-tech’ treatments
  - Death with dignity end-of-life care not emphasized

Hospitals

- Most deaths occur in hospitals.
- Most dying receive some hospital care.
- Acute care facilities regard death as failure.
- Physicians frequently do ask patients about their wishes for end-of-life care.

- Differences among hospitals make it improbable that a single model for end-of-life care can be recommended or mandated.

Nursing Homes/Long Term Care Facilities

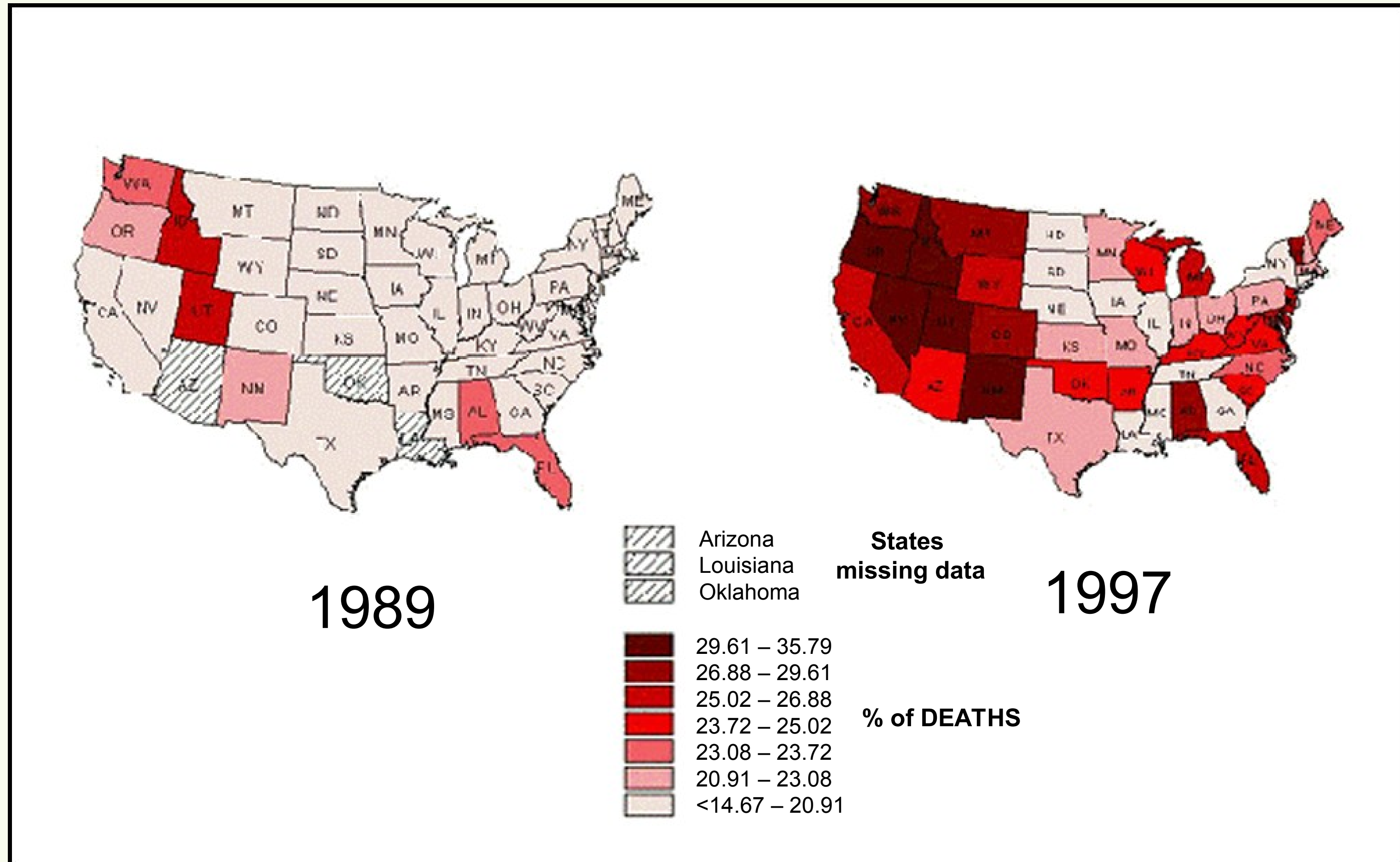
- Nursing homes are increasingly the site of death for many Americans.
- The number of older people most at risk for nursing home admissions grow as hospitals and managed care plans continue to decrease lengths of hospital stay
  - These decreases are due to federal policy changes in the 1980s.
- 1.5 million Americans are living in nursing homes today.
- 40% of Americans will die in nursing homes by 2020.
- The number of nursing home deaths increased markedly from 1989 to 1997 and will continue to raise figures 1 & 2.

(Brock & Foley)

Home Care

- With hospice
  - Intended to help people die comfortably at home
  - Most care for adults, especially cancer patients
  - 1,100 hospices in 1996
- Without hospice
  - Patients with serious chronic illness (e.g., congestive heart failure, chronic obstructive pulmonary disease) who do not qualify for hospice, also likely to die from their illness.

Proportion of Deaths Occurring at Home: 1989 vs. 1997



Inpatient Hospice Care

- Inpatient Hospice Care
  - Becoming more common in the US
  - Respite care provided in acute acre hospital settings
    - Limitations on length of stay
    - Primarily for management of uncontrolled symptom distress

Coordination of Care

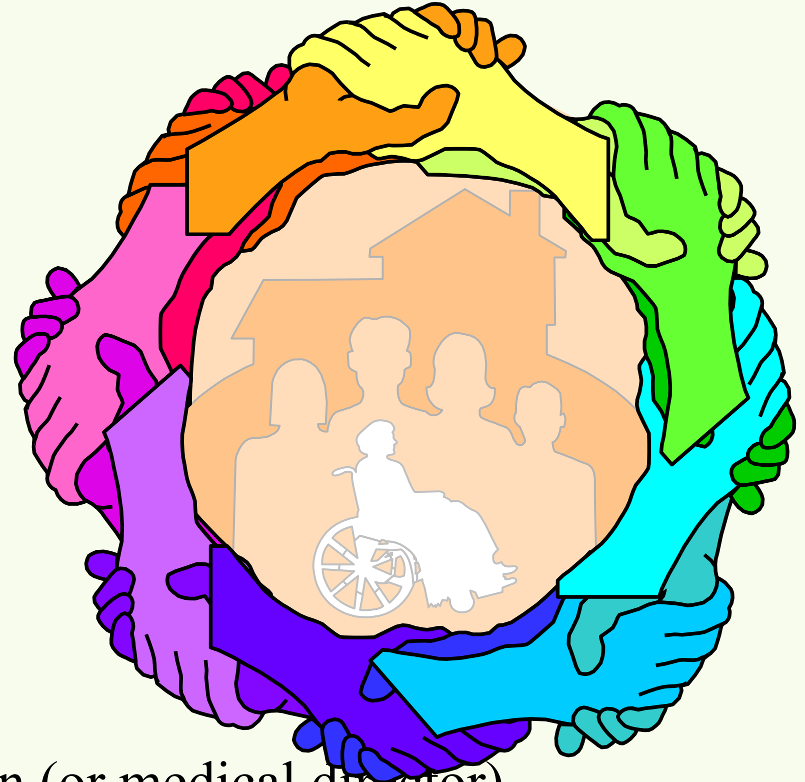
- Patients move among many health care settings
  - Care provided by different physicians, nurses, and other personnel.
  - Coordinating care during transitions from one setting to another presents major challenges
  - Different organizations and funding sources are involved.
  - Creating 'seamless' transitions
    - Interdisciplinary Palliative Care
    - Home Hospice Teams
      - Must have primary caregiver (family or other)
    - Inpatient Palliative Care Teams
    - Managed Care

Creating 'Seamless' Transitions

- Patients often move among many health care settings:
  - From being independent to acute care facilities, long term care facilities, outpatient treatment (curative or palliative), home health care and hospice settings as their disease trajectory progresses.
- Different organizations and funding sources are involved – creating barriers to optimal end-of-life care.
- A solution to this care coordination problem is the involvement of Interdisciplinary Palliative Care or Hospice Teams.

Interdisciplinary Palliative Care or Hospice Teams

- They are typically comprised of:
  - Patient
  - Patient’s family or caregiver
  - Patient’s personal physician
  - Nurses (RN’s & LPN’s)
  - Home health aides
  - Social workers
  - Clergy or other counselors
  - Pharmacists
  - Trained volunteers
  - Palliative care or hospice physician (or medical director)
  - Speech, physical, and occupational therapists, if needed.



Levels of Care Systems: A New Future for End-of-Life Care

- Community, Regional and National
- Approaching Death by the Committee
  - Effort is needed on multiple levels — within individual health care and other organizations and government agencies and through cooperative community, regional, and national initiatives.
  - Resources to promote integration of care across settings
  - A system that reflects the understanding that there is not just one way to care for dying patients.

(Field & Cassel, 1997)