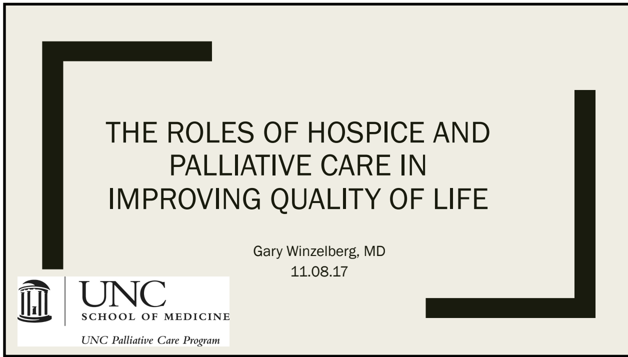
THE ROLES OF HOSPICE AND PALLIATIVE CARE IN IMPROVING QUALITY OF LIFE
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11.08.17
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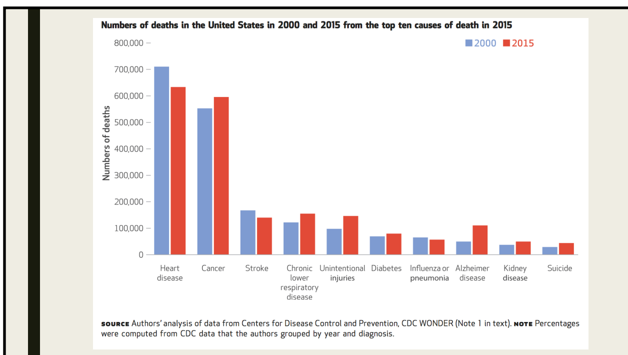
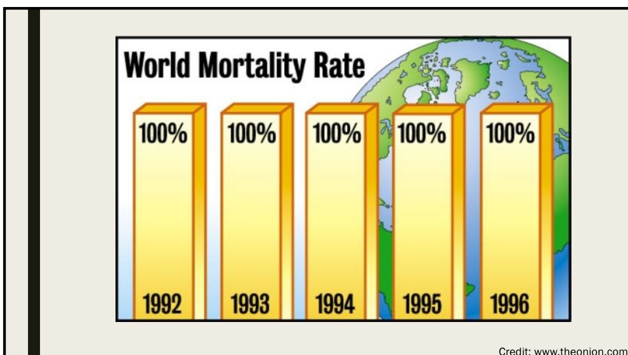
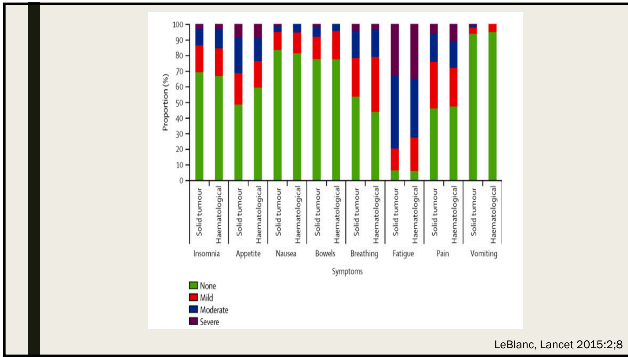
UNC Palliative Care Program

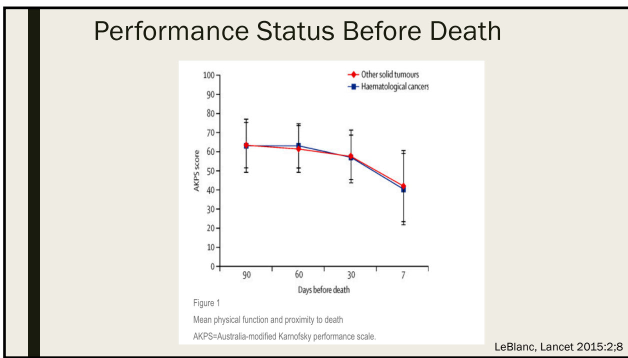

Numbers of deaths in the United States in 2000 and 2015 from the top ten causes of death in 2015
2000
2015
Numbers of deaths
800,000
700,000
600,000
500,000
400,000
300,000
200,000
100,000
0
Heart disease
Cancer
Stroke
Chronic lower respiratory disease
Unintentional injuries
Diabetes
Influenza or pneumonia
Alzheimer disease
Kidney disease
Suicide
SOURCE Authors' analysis of data from Centers for Disease Control and Prevention, CDC WONDER (Note 1 in text). NOTE Percentages were computed from CDC data that the authors grouped by year and diagnosis.


World Mortality Rate
100%
100%
100%
100%
100%
1992
1993
1994
1995
1996
Credit: www.theonion.com



LeBlanc, Lancet 2015:2;8

Performance Status Before Death



LeBlanc, Lancet 2015:2;8

End of Life Cancer Care

816 consecutive patients treated at MD Anderson

- *Solid tumor (86%) – incurable at presentation*
- *Heme malignancy (14%) – first recurrence*

Treatment last 14 days of life	Heme malignancy (%)	Solid tumor (%)
Chemotherapy*	21	6
Targeted therapy*	17	5
Combination (C+T)*	28	10

Hui et al.

End of Life Cancer Care

Treatment last 30 days of life	Heme malignancy (%)	Solid tumor (%)
ED Visits	54	43
>2 ED visits	*15*	*12*
Any hospital admission*	81	47
*>2 hospital admissions**	*23*	*10*
ICU admission*	47	16
>14 days hospitalization*	38	8
Hospital death*	47	16
ICU death*	33	4

*p<.001

Objectives

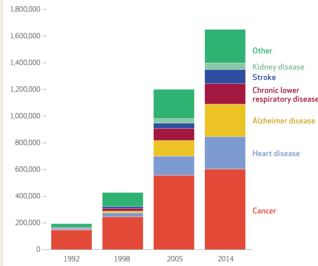
- Historical background
- Review clinical components
  - *Relationship between hospice & palliative care*
- Barriers to service delivery
- Evidence for impact on quality of life

Dame Cicely Saunders

- 1918-2005
- Nurse
- Social worker
- Physician
- Founded St. Christopher's Hospice in London
- First patient admitted on July 13, 1967

Hospice in the United States

- 1965 – Medicare and Medicaid
- 1972 – Medicare coverage for End Stage Renal Disease
- 1974 – Connecticut Hospice
- 1976 – NEJM paper about DNR order; Quinlan case
- 1982 – Medicare hospice benefit
- 1991 – Patient Self-Determination Act



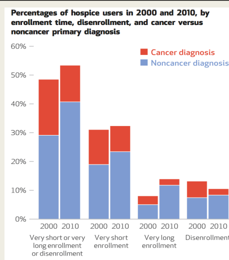
Hospice Philosophy

- Vision – individuals & families facing serious illness, death, and grief experience the best that humankind can offer
  - *Model for quality, compassionate care at the end of life*
  - *Team approach of expert medical care, pain management and emotional & spiritual support tailored to the patient's wishes*
- Goal – support every day to become the best day possible
  - *Independent of number of days*

National Hospice and Palliative Care Organization

Hospice Eligibility (Medicare)

- Certification by a physician as patient having:
  - *Terminal illness*
  - *Expected to live for six months or less with the disease taking its usual/normal course*
- Election periods
  - *Initial 90 day period*
  - *Subsequent 90 day period*
  - *Unlimited number of subsequent 60-day periods*



General Eligibility Guidelines

- Patient/family focus on symptom relief rather than cure
- Disease progression
- Weight loss, albumin < 2.5
- Dependence in at least 2 ADLs
- Need for frequent hospitalizations, office, ER visits
- Progressive/unhealing Stage III or IV pressure ulcers
- Hospital developed with cancer as model condition
  - *Development of other disease-specific criteria*

Hospice Benefits

- Multidisciplinary team supports patient and family
  - *Usually at home*
- All medications, equipment and supplies needed for patient comfort and related to the hospice-eligible diagnosis
- Bereavement support offered for 12 months after death

Home Hospice Services

- 24 hour on-call
- RN visits: ≤ 3/week + prn
- Home health aide: < 2 hr/day
- Social worker: every 2 weeks
- Chaplain: every 2-4 weeks
- Volunteer: 2-4 hours/week
- MD: prn
- Therapists: prn

**Depends on hospice organization & patient needs/preferences

Inpatient Hospice

- Pain & symptoms can’t be effectively managed in the patient’s home or other residential setting
- Requires skilled nursing care 24 hrs/day to maintain comfort
- Short-term intervention
- No limit on number of days, episodes
- All costs covered

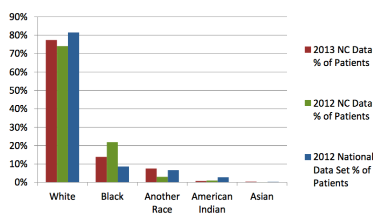
Other Hospice Services

- Respite
  - *Up to 5 days per billing period*
  - *Usually provided in nursing home or hospice facility*
  - *Provide rest for caregiver*
  - *Home temporarily inadequate to meet care needs*

- Continuous
  - *Provided only during periods of crisis to maintain patient at home*
  - *At least 8 hours in a 24 hour period*
  - *At least 50% care must be provided by nurse*

Hospice Care Barriers

- Preference for disease-directed treatments
- Challenges with prognostication
- Inadequate caregiving at home
- Hospice doesn't pay for room & board in nursing homes, assisted living facilities



Carolinas Center for Hospice and End of Life Care
Cchospice.org

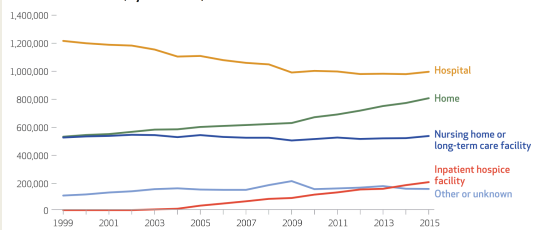
Addressing Hospice Concerns

- Ask about experiences of loved ones, friends
- First, identify comfort & dignity as primary or exclusive goals
- Then, discuss, recommend hospice as service to support goals
- Focus on helping make every day the best day possible
  - *Maximizing quality of life*
  - *Living until death*
- Reassure that services can be discontinued
- Note that prognostication is inherently inexact

Hospice Improves Outcomes

- Hospice associated with:
  - *Higher quality of care, quality of dying*
  - *Increased use of symptom treatments*
  - *Decreased restraints, tube feeds, IV therapies, hospitalizations*
  - *Death in site of choice; out of hospital*
- No change in survival

Teno JM, JAGS 2011; Kiely DK, JAGS 2010; Shega J, JPSM 2008;
Miller SC, JPSM 2003; Miller SC, AJM 2001; Baer WM, JAGS 2000; Munn JC, JAGS 2006

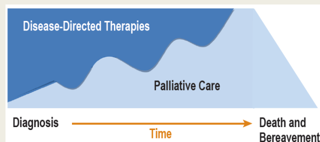


Why isn't hospice enough?

- SUPPORT study (JAMA 1995) - 5 teaching hospitals in US
- 9,105 hospitalized adults with 9 life-threatening diagnoses
- 47% six-month mortality rate
- 50% patients had moderate-severe pain prior to hospital death per families
- 38% hospital deaths included $\geq$ 10 days in ICU
- 47% physicians knew when patients preferred DNR
- 46% DNR orders written within 2 days of death
- Intervention with specially trained nurse = no impact

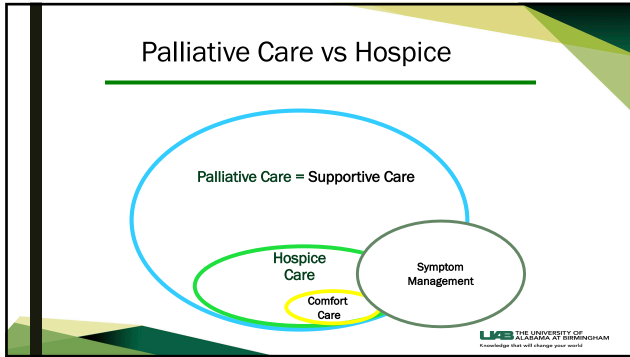
Disease-Directed Care (Goal = Cure)	End of Life Care (Hospice)

What is Palliative Care?



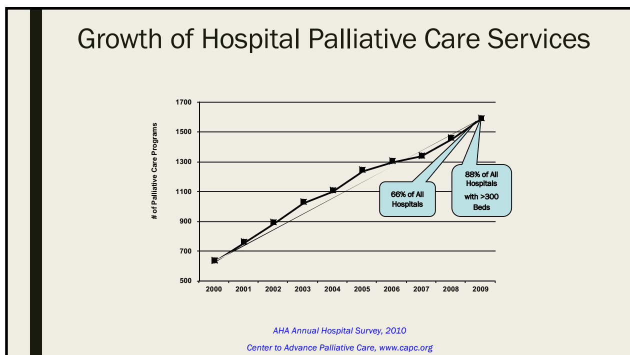
- Specialized **medical care** for people with serious illness
- Focuses on **improving quality of life** for patients **of any age or diagnosis** and their **families.**
- Provides **relief of symptoms, pain and stress** of a serious illness

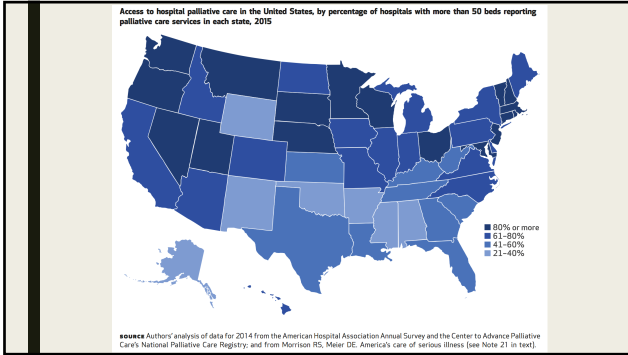
- Provided by a **team of doctors, nurses and other specialists**
- Work together with patient's other clinicians as **an extra layer of support.**
- **Provided along with curative treatment.**



Hospice & Palliative Care Compare/Contrast

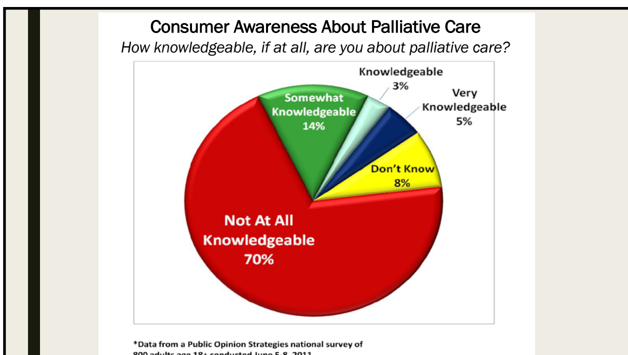
Hospice	Palliative Care
Pain & Symptom Management	Pain & Symptom Management
Patient & Family Support	Patient & Family Support
Communication/Decision Making	Communication/Decision Making
Comprehensive insurance benefit: Meds/Equipment/Home supports	Limited insurance coverage for physician consultation; reliance on health system support
Prognosis < 6 months if disease follows expected course	Independent of Prognosis
Goal: exclusively comfort. Avoid hospitalizations	Co-exists with disease-based evaluation/treatment, hospitalizations
Where: Home, long-term care, inpatient facility beds	Where: primarily hospitals Developing in outpatient clinics, home, long-term care





UNC Hospice & Palliative Care

- Chapel Hill
  - *Hospital consult service*
  - *Cancer hospital clinic*
- Triangle
  - *Hospice: home & inpatient facility (Pittsboro)*
  - *REACH: home palliative care*



Palliative Care Components

- Symptom assessment & management
  - *Pain*
  - *Non-pain symptoms (physical & mental health)*
- Support – for patients and families
  - *Emotional*
  - *Coping*
  - *Practical*
- Communication & decision-making
  - *Illness understanding*
  - *Advance care planning*
  - *Goals of care – align decisions with (achievable) priorities*

Consider Palliative Care . . .

Patients with serious illness:

- Critical illness in ICU / frequent acute admissions
- Progressive incurable cancer
- Cancer compounded by frailty and multi-morbidity

“Death in the next year wouldn’t surprise me.”

Introducing Palliative Care to Patients and Families

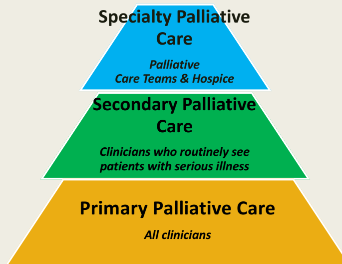
- Don’t ask if patients/families want to see palliative care
- Do state indication(s) for palliative care
  - *Symptom relief*
  - *Improving quality of life*
  - *Extra layer of support*
- Emphasize integration of palliative care with primary team

Primary vs Specialty Palliative Care

- Challenges –
  - *Demand for palliative care > supply*
  - *Undermine relationships if palliative care replaces primary physician*
  - *Promote care fragmentation*
- Primary = skills all clinicians should have
  - *Foundational symptom assessment, communication skills*
- Specialty = skills for more complex & difficult cases
  - *Refractory, multiple symptoms*
  - *Address conflicts – goals of care, treatment plan, illness understanding*
- Where does primary palliative care end & specialty care begin?
  - *May depend on individual health professional*

Quill TE. Abernethy AP. NEJM 2013.

Who Provides Palliative Care?



Palliative Care Outcomes

> 10 randomized controlled trials; outpatient & hospital care

Patients with <u>advanced cancer</u>
- *Solid tumor (lung, gastrointestinal)*
- *Hematopoietic stem cell transplant*

Benefits across multiple trials:
- *Improves quality of life (timing 2-24 weeks)*
- *Reduces depression*
- *Increases care satisfaction*

Benefits in $\geq$ 1 trial:
- *Survival*
- *Decreased use of chemotherapy within 60 days of death*
- *Longer hospice enrollment*
- *Discussed prognosis & end of life wishes with oncologist*

No adverse outcomes from early palliative care involvement

El-Jawahri A et al. JAMA 2016; Temel JS et al. J Clin Oncol 2016. Greer JA et al. J Clin Oncol 2011; Temel JS et al. NEJM 2010; Bakitas M et al. JAMA 2009. Ferrell BR et al. J Clin Oncol 2016.

Hospital Palliative Care Improves Outcomes for Serious Illness

Specialty Palliative Care consultation (3 RCTs)

- + quality of communication
- + Advance care planning documentation of preferences
- + family satisfaction with care
  - *Earlier consultations were associated with higher satisfaction*
- Reduced ICU admissions and cost
- No change in survival

Ringdal JPSM 2002; Engelhardt Am J Manag Care 2006; Gade JPM 2008; Zimmerman JAMA 2008

Outpatient Palliative Care Improves Cancer Outcomes

- RCT metastatic lung cancer care with early palliative care co-management vs standard cancer care
  - Improved quality of life
  - Reduced major depression
  - Reduced 'aggressiveness' of treatment
    - Chemotherapy < 14 days before death
    - No hospice care
    - Hospice < 3 days before death
  - *Improved survival (11.6 mos. vs 8.9 mos.)*

Temel NEJM 2010

Palliative Care Impact on Patients Receiving Stem Cell Transplants

- Median hospitalization duration = 20 days (range 12-102)
- Median palliative care visits during first 2 weeks in hospital = 4 (range 2-7)
- 2 weeks post-transplant:
  - *Smaller decrease in QOL in pts receiving palliative care*
  - *Less anxiety*
  - *Less increase in symptom burden and depression*
- 3 months post-transplant:
  - *Higher QOL*
  - *Less depression*

El-Jawahri A et al. JAMA 2016

Visit Content and Symptoms Addressed

- Initial Visit Content:
  - *Rapport building (99%)*
  - *Symptoms (89%)*
  - *Coping (85%)*
  - *Illness Understanding (12%)*
  - *Treatment decision-making (2.5%)*
  - *Advance care planning (2.5%)*
- Symptoms addressed
  - *Nausea (68%)*
  - *Pain (65%)*
  - *GI (50+%)*
  - *Fatigue (38%)*

American Society of Clinical Oncology 2016 Clinical Practice Guideline

- Inpatients and outpatients with advanced cancer should receive dedicated palliative care services
  - *Early in disease course*
  - *Concurrent with cancer treatment*
- Referral to interdisciplinary palliative care teams is optimal

Ferrell BR et al. J Clin Oncol 2016

Summary

- Hospice and palliative care – interrelated yet distinct services
- Need to promote palliative care skills for all health professionals
- For patients with cancer and other serious illnesses, specialty palliative care:
  - *Improves quality of life*
  - *Decreases symptom burden*
  - *Reduces burdensome interventions towards end of life*