Palliative Care and Hospice for the Patient with Cancer

Gary Winzelberg, MD MPH
Jennifer Hanspal, RN BSN MS OCN
10.07.2020

Premise

- Over the past 50 years, the fields of hospice and palliative care have had a significant impact on improving quality of life and care for patients with cancer.

Outline

- Historical developments resulting in development of hospice and palliative care
- Clinical components of hospice and palliative care
  - What does the patient and family experience?
- Outcomes of hospice and palliative care for patients

UNC SCHOOL OF MEDICINE

3

Evolution of Life Expectancy & Causes of Death

- 1900: Life expectancy = 47 years
- Top 3 causes of death = pneumonia/flu, tuberculosis, gastrointestinal infections

- 2010: Life expectancy = 79 years
- Top 3 causes of death = heart disease, cancer, lung disease
- Dementia likely underrepresented

UNC SCHOOL OF MEDICINE

4

Factors Contributing to Increased Life Expectancy

- Public health (sanitation, water)
- Vaccinations
- Disease-directed treatments
  - Antibiotics
  - Heart disease
  - Cancer – chemotherapy, immunotherapy

Dying as a Chronic Condition

- Physical and cognitive decline over months – years
- Life prolonging interventions
  - Intensive care units
  - Mechanical ventilation
  - Kidney dialysis
- Family caregiving and financial impact

Dame Cicely Saunders

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

Cicely Saunders (Richmond C. thebmj. 07.18.2005)

- "It appears that many patients feel deserted by their doctors at the end. Ideally the doctor should remain at the centre of a team who work together to relieve where they cannot heal, to keep the patient's own struggle within his compass and to bring hope and consolation to the end." [1958]

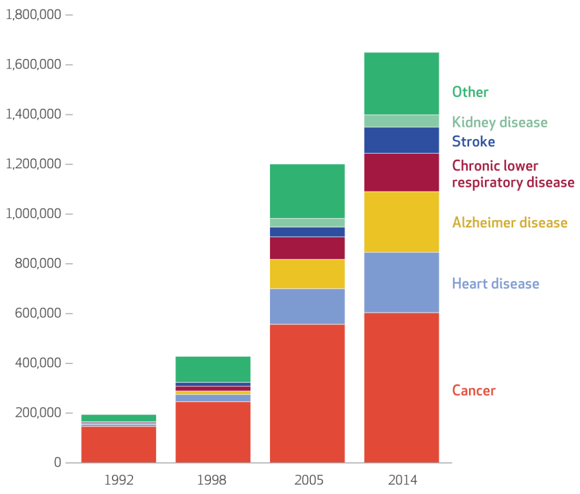
Hospice in the United States

- 1965 – Medicare and Medicaid
- 1969 – Kubler Ross, On Death and Dying (5 Stages of Grief)
- 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

UNC SCHOOL OF MEDICINE

Numbers of Hospice Users by Primary Diagnosis

Numbers of hospice users by primary diagnosis, selected years



SOURCE Authors' analysis of data from the following sources: For 1992 and 1998, Government Accountability Office. Medicare: More beneficiaries use hospice but for fewer days of care [Internet]. Washington (DC): GAO; 2000 Sep [cited 2017 Jun 21]. (Pub. No. GAO/HEHS-00-182). Available from: http://www.gao.gov/new.items/he00182.pdf. For 2005 and 2014, National Hospice and Palliative Care Organization. NHPCO's facts and figures (see Note 48 in text).

UNC SCHOOL OF MEDICINE

Hospice Philosophy

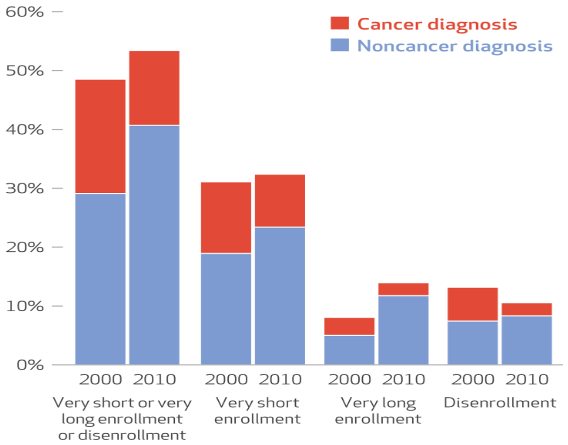
- Vision – individuals & families facing serious illness, death, and grief experience the best that humankind can offer
  - Model for quality, compassionate care at the end of life
  - Team approach of expert medical care, pain management and emotional & spiritual support tailored to the patient’s wishes
  - Team = nursing, medicine, social work, chaplains, volunteers
- 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
- Patient desire to pursue comfort care over disease treatment
- Election periods
  - Initial 90 day period
  - Subsequent 90 day period
  - Unlimited number of subsequent 60-day periods

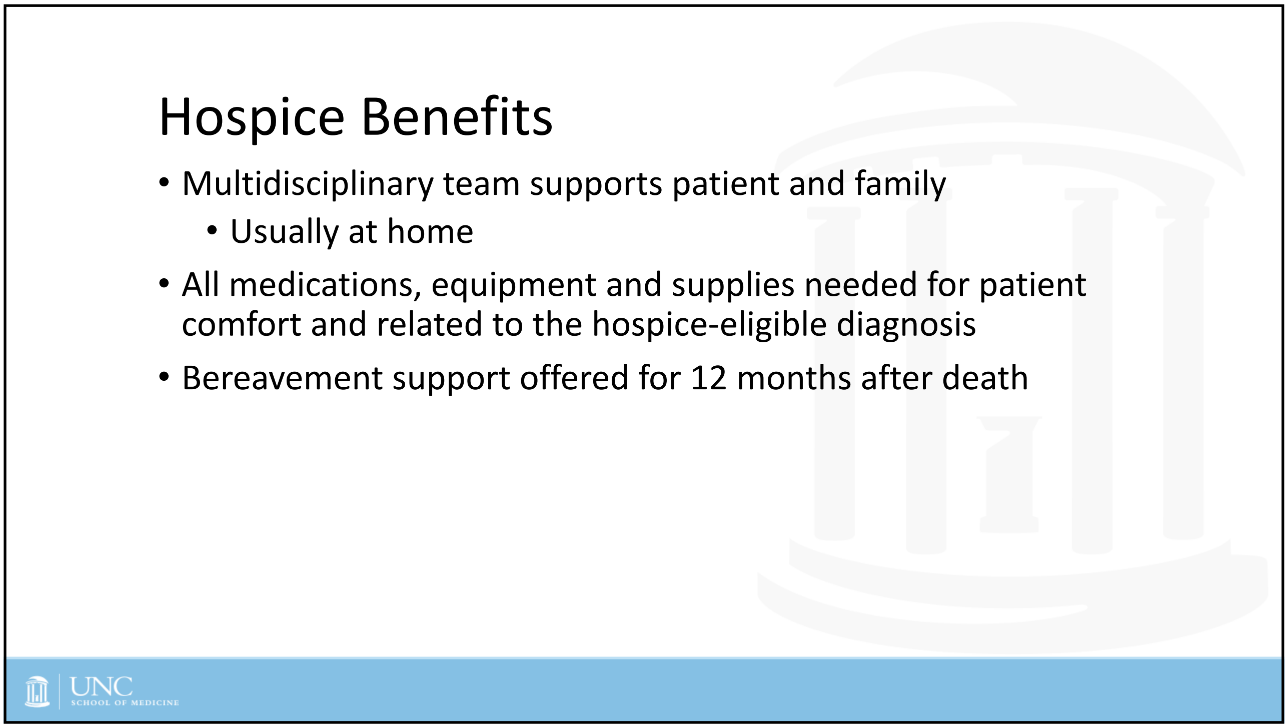
Percentages of hospice users in 2000 and 2010, by enrollment time, disenrollment, and cancer versus noncancer primary diagnosis



SOURCE Authors' analysis of data from Aldridge MD, et al. Has hospice use changed? (see Note 50 in text). **NOTES** "Very short enrollment" is defined as hospice enrollment for one week or less. "Very long enrollment" is defined as hospice enrollment for longer than six months. "Disenrollment" is defined as hospice care ending before the patient's death. Each difference between 2000 and 2010 percentages is significant ($p < 0.001$), as indicated by *t*-tests.

General Eligibility Guidelines

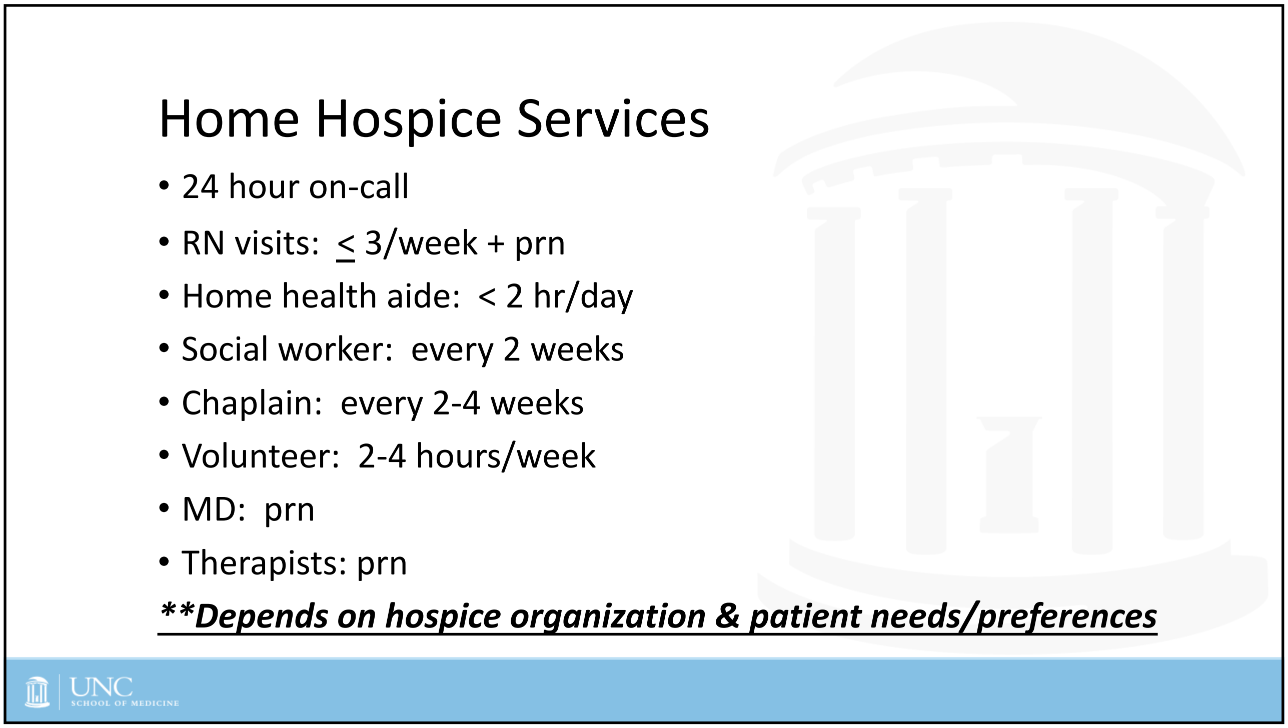
- Patient/family focus on symptom relief rather than cure
- Disease progression
- Weight loss, albumin < 2.5
- Dependence in at least 2 ADLs
- Need for frequent hospitalizations, office, ER visits
- Progressive/non-healing Stage III or IV pressure ulcers
- Hospital developed with cancer as model condition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

UNC
SCHOOL OF MEDICINE



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***

UNC
SCHOOL OF MEDICINE

Inpatient Hospice

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

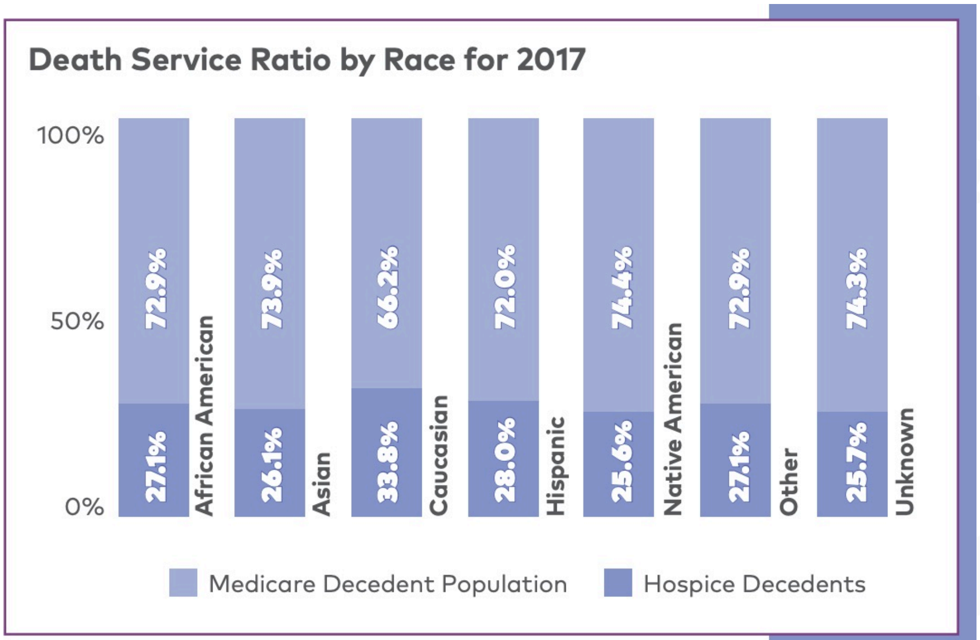
Other Hospice Services

- 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

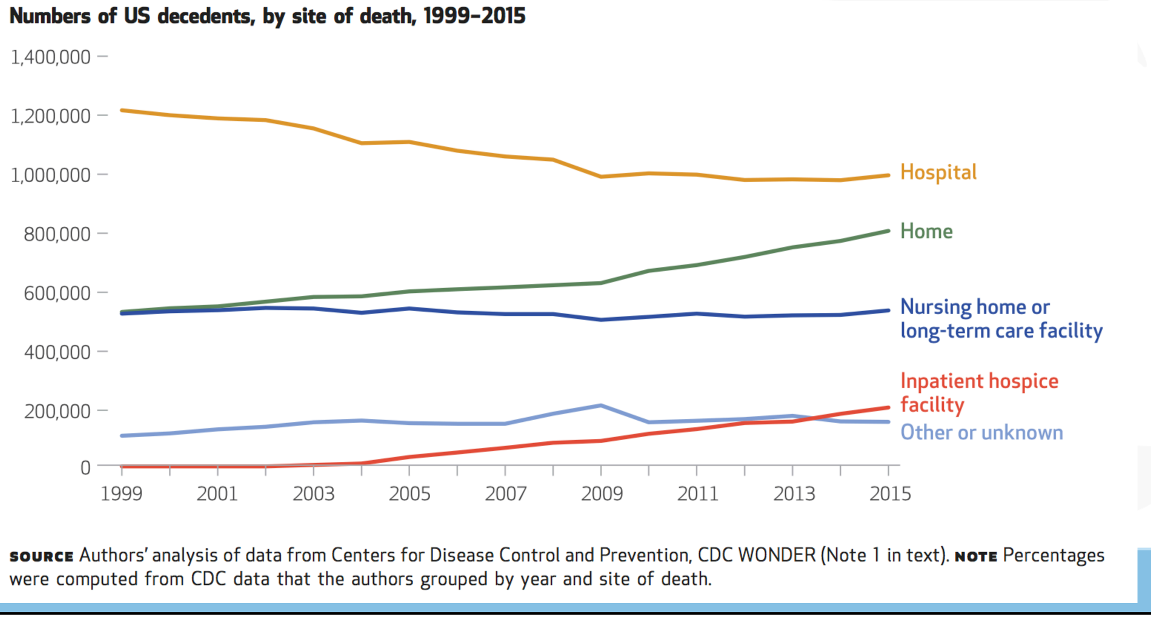


Percentage of Medicare decedents who died under hospice care by race.

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

Deaths by site of death, 1999-2015



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 site of death.

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 ≥ 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

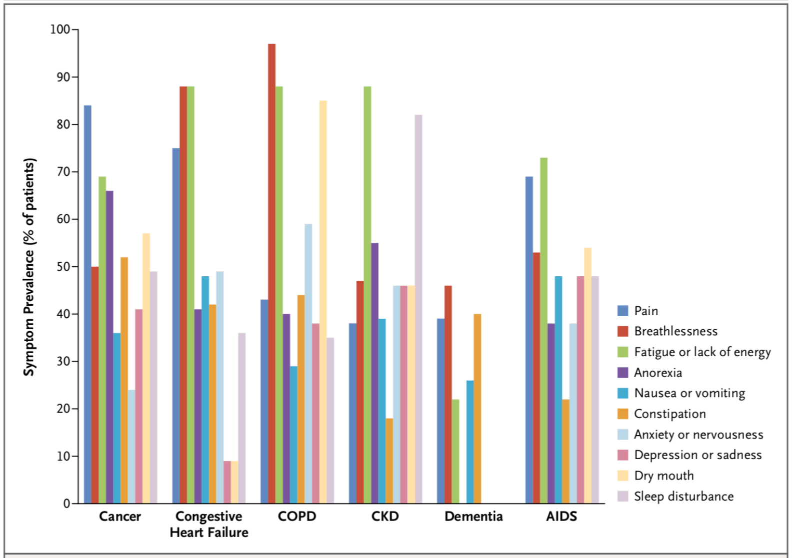
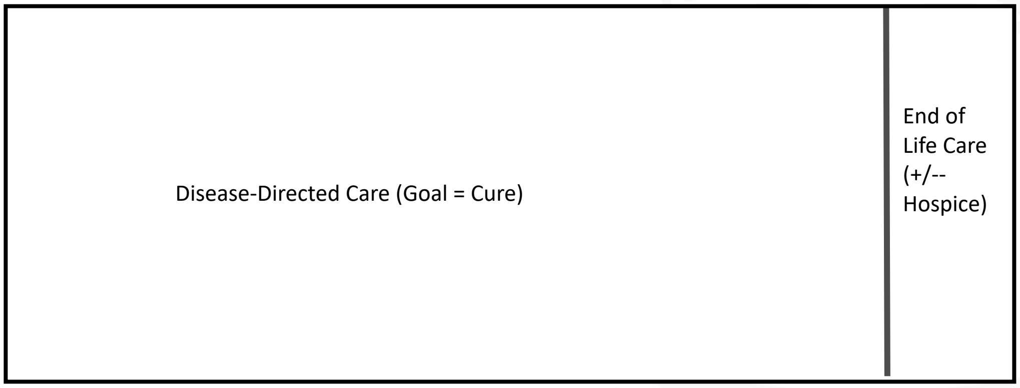


Figure 1. Symptom Prevalence in Advanced Illness.

Data are from representative studies of symptom prevalence among patients with cancer,[8-12] congestive heart failure,[13,14] chronic obstructive pulmonary disease (COPD),[15] chronic kidney disease (CKD),[13,14] or dementia[16,17] and among patients who received highly active antiretroviral therapy for the acquired immunodeficiency syndrome (AIDS).[18] Self-reported data regarding some symptoms were unavailable for patients with dementia.

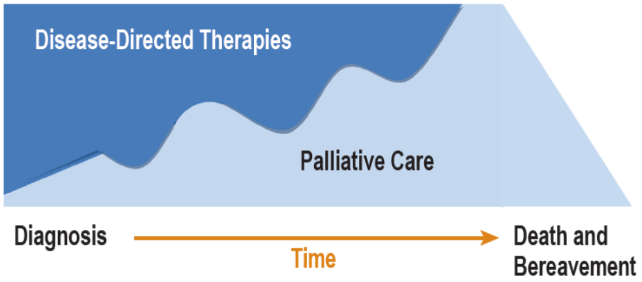
Kelley AS. NEJM 2015



Disease-Directed Care (Goal = Cure)

End of Life Care (+/-- Hospice)

What is Palliative Care?

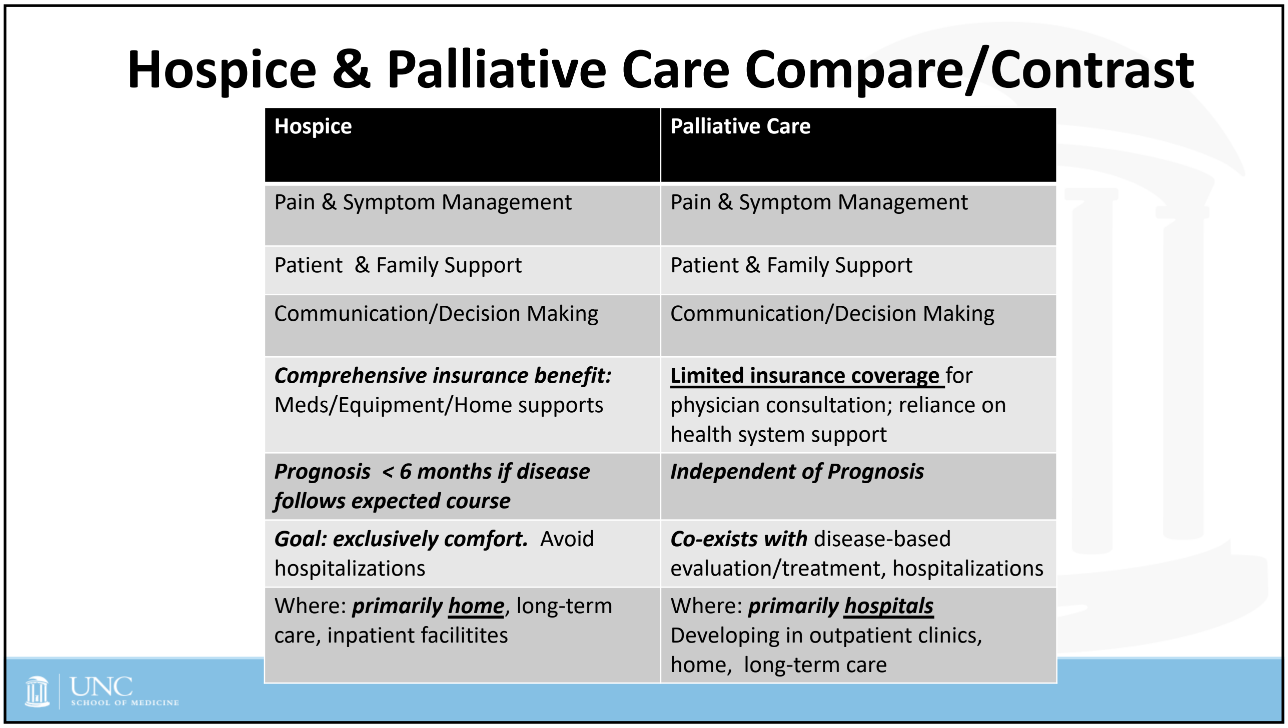


- Specialized **medical care** for people with serious illness
- Focuses on **improving quality of life** for patients **of any age or diagnosis** and their **families.**
- Provides **relief of symptoms, pain and stress** of a serious illness

- 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.**

Palliative Care Components

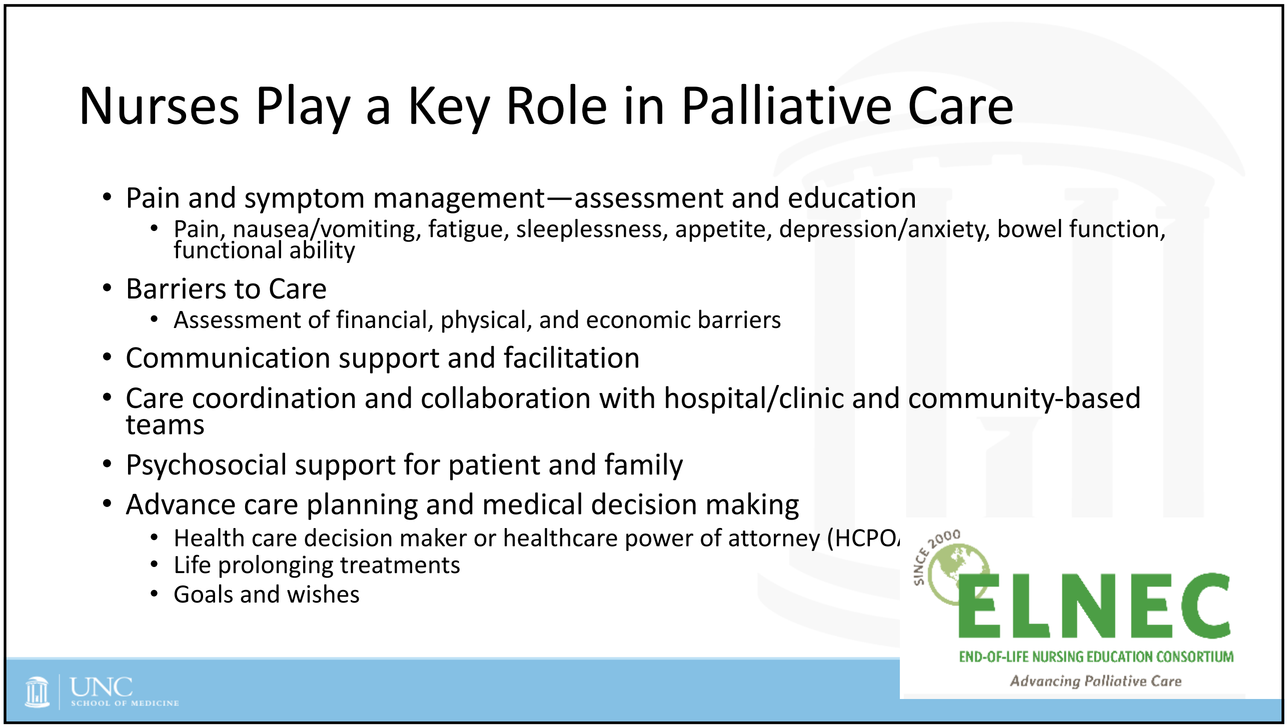
- Symptom assessment & management
  - Pain
  - Non-pain symptoms (physical & mental health)
- Support – for patients and families
  - Emotional
  - Coping
  - Practical
- Communication & decision-making
  - Illness understanding
  - Advance care planning
  - Goals of care – align decisions with (achievable)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



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: ***primarily home***, long-term care, inpatient facilitites	Where: ***primarily hospitals*** Developing in outpatient clinics, home, long-term care

UNC SCHOOL OF MEDICINE



Nurses Play a Key Role in Palliative Care

- Pain and symptom management—assessment and education
  - Pain, nausea/vomiting, fatigue, sleeplessness, appetite, depression/anxiety, bowel function, functional ability
- Barriers to Care
  - Assessment of financial, physical, and economic barriers
- Communication support and facilitation
- Care coordination and collaboration with hospital/clinic and community-based teams
- Psychosocial support for patient and family
- Advance care planning and medical decision making
  - Health care decision maker or healthcare power of attorney (HCPO
  - Life prolonging treatments
  - Goals and wishes

SINCE 2000 ELNEC
END-OF-LIFE NURSING EDUCATION CONSORTIUM
Advancing Palliative Care

UNC SCHOOL OF MEDICINE

Care Coordination and Collaboration

CHCS Center for Health Care Strategies, Inc. ©2016 Center for Health Care Strategies.

- Internal and external teams
  - Appointments, changes in care, hospitalizations,
- Healthcare Teams
  - Partnering with teams to achieve expert symptom management and ensure the patients goals align with treatment options.
- Patients
  - Offers a sense of control
  - Helps attain spiritual peace
  - Allows space and time to get affairs and finances in order
  - Strengthens or resolves relationships with loved ones
  - Reassurance that their life has meaning

Advance Care Planning

Developed by PREPARE™ for your care

- Hope for the best…Prepare for the worst
  - Hope for the best—review treatments that may prolong life and relieve suffering
  - Prepare for the worst—What would be left undone? Who would make decisions if you could not make them? What would be your wishes be regarding aggressive treatments, such as CPR?
- Understand cultural differences in talking about death and dying
  - Views of death—cycle of life or try to avoid
  - Social customs
- NC Prepare for Your Care
  - https://prepareforyourcare.org/welcome
- The Conversation Starter Kit
  - https://theconversationproject.org/starter-kits/
- Vital Talk
  - https://www.vitaltalk.org/

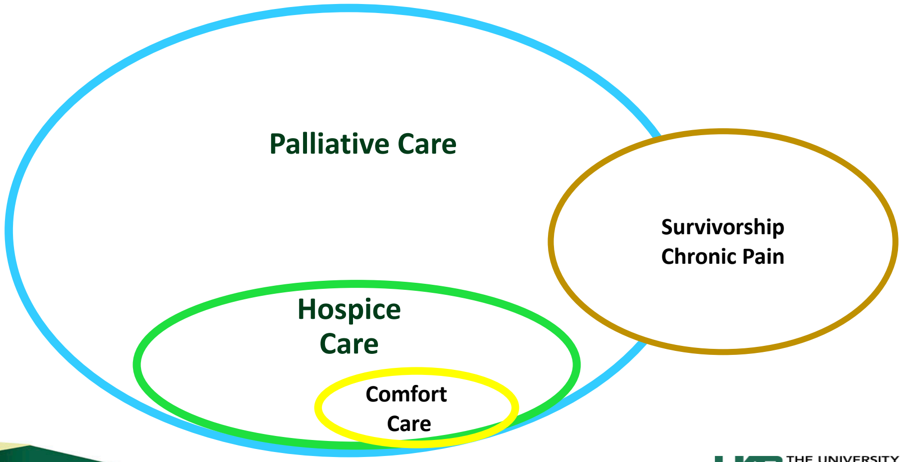
VITALtalk


Your Conversation Starter Kit

When it comes to end-of-life care, talking matters.

Institute for Healthcare Improvement the conversation project

Serious Illness Care Continuum



THE UNIVERSITY OF ALABAMA AT BIRMINGHAM
Knowledge that will change your world

Top 10 Things PC Clinicians Wished Everyone Knew About Palliative Care

(Strand JJ et al. Mayo Clin Proc 2013)

1. PC can help address the multifaceted aspects of care for patients facing a serious illness.
2. PC is appropriate at any stage of serious illness.
3. Early integration of PC is becoming the new standard of care for patients with advanced cancer.
4. Moving beyond cancer: PC can be beneficial for many chronic diseases.
5. PC teams manage total pain.

UNC SCHOOL OF MEDICINE

Top 10 Things…

6. Patients with a serious illness have many symptoms that PC teams can help address.
7. PC can help address the emotional impact of serious illness on patients and their families.
8. PC teams assist in complex communication interactions.
9. Addressing the barriers to PC involvement: patients' hopes and values equate to more than a cure.
10. PC enhances health care value.

Consider

- Which of the following patents could benefit from palliative care?
  - A. 64 y/o with stage 2 prostate cancer and congestive Heart failure (CHF), high blood pressure (HTN), and diabetes (DM)?
  - 32 y/o with acute myelogenous leukemia (AML)?
  - 57 y/o with newly diagnosed stage 3 breast cancer patient with 3 children and recently divorced
  - 76 y/o with chronic obstructive pulmonary disease (COPD) and stage 3 lung cancer

Answer

- All!
- A. CHF is a chronic condition requiring frequent symptom management checks and often results in multiple hospitalizations
- B. AML pt is considered an AYA (Adult and Young Adolescent) patient with unique needs facing a life threatening diagnosis
- C. Breast cancer patient with recent and significant life life changes including cancer diagnosis and loss of partner/caregiver and continued childcare responsibilities
- D. COPD is a chronic condition requiring frequent symptom management checks and often results in multiple hospitalizations

Palliative Care Outcomes

- > 10 randomized controlled trials; outpatient & hospital care
- Patients with advanced cancer
  - 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 ≥ 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 in any trials

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.

Association Between Palliative Care and Patient and Caregiver Outcomes

(Kavalieratos D et al. JAMA 2016)

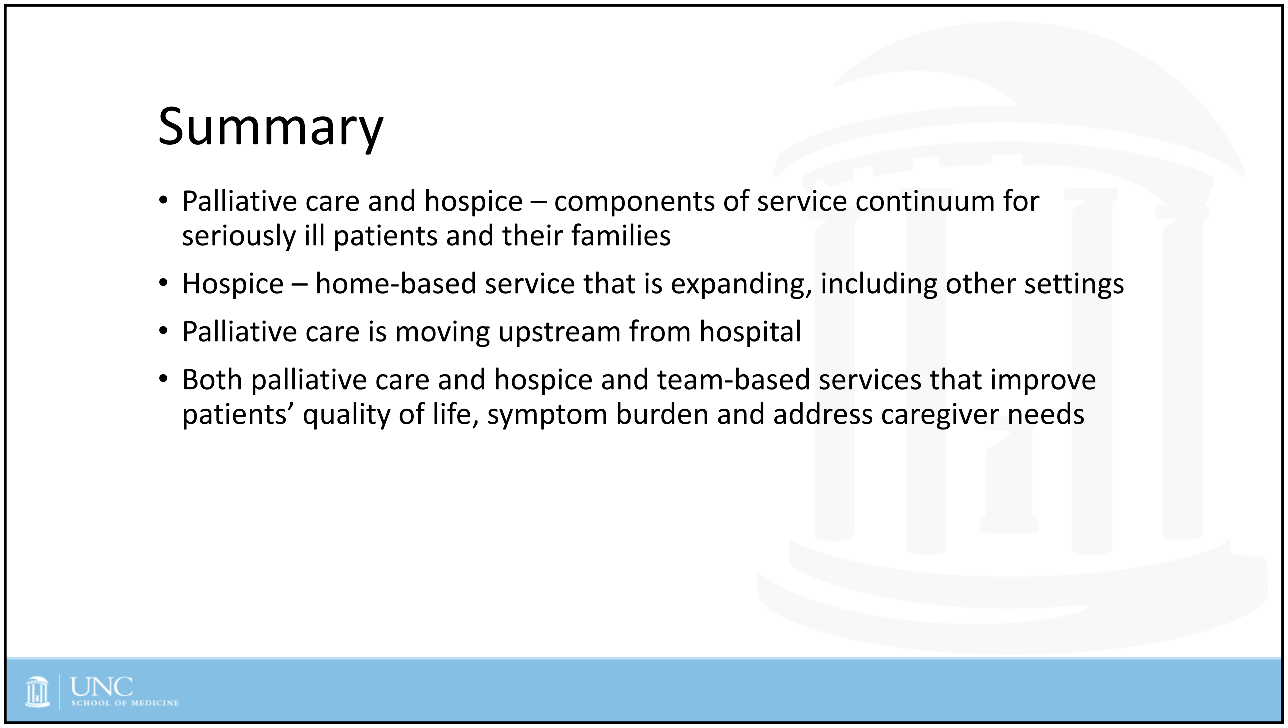
- Systematic review/meta analysis
- 43 RCTs, 12,731 patients (mean age 67) & 2,479 caregivers
- Cancer, Heart Failure, HIV (1), MS (1)
- Improved patient QOL at 1 to 3 month follow up
- Improved symptom burden at 1 to 3 month follow up
- No association with survival
- Consistent improvements in:
  - Advance care planning
  - Patient and caregiver satisfaction
  - Lower health care utilization

UNC SCHOOL OF MEDICINE

Patient - NF

- 47 year old male, diagnosed with Stage 4 lung cancer in 2017
- Moved to NC in 2019 to support his wife – first palliative care visit
- Clinic and hospital visits for symptom management integrated with cancer treatments
- 2020 – cancer progression, ongoing discussion about care goals
- Intestinal obstruction from cancer
- Transition to inpatient hospice facility
  - Wife stayed 24/7, visits from cat
  - Lived for 1+ month

UNC SCHOOL OF MEDICINE



Summary

- Palliative care and hospice – components of service continuum for seriously ill patients and their families
- Hospice – home-based service that is expanding, including other settings
- Palliative care is moving upstream from hospital
- Both palliative care and hospice and team-based services that improve patients’ quality of life, symptom burden and address caregiver needs