

Painweek.

ADVANCED EDUCATION

CERTIFICATION SERIES

PALLIATIVE CARE



Introduction to Palliative Care

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Titles and Affiliations

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Disclosures



Learning Objectives

At the conclusion of this presentation the participant will be able to:

Define:: hospice and palliative care.



Describe:: the conditions of participation in hospice and palliative care.



Describe:: the benefit of early integration of palliative care with serious illness.

What is hospice?

- “Hospice affirms the concept of palliative care as an intensive program that enhances comfort and promotes the quality of life for individuals and their families.
- When cure is no longer possible, hospice recognizes that a peaceful and comfortable death is an essential goal of health care.
- Hospice believes that death is an integral part of the life cycle and that intensive palliative care focuses on pain relief, comfort and enhanced quality of life as appropriate goals for the terminally ill.
- Hospice also recognizes the potential for growth that often exists within the dying experience for the individual and his/her family and seeks to protect and nurture this potential.”

Hutcheson. *Prim Care*. 2011;38(2):173-182.



A brief history of “hospice”

- From the Latin word “hospes” - means both “guest” and “host” (11th century)
- Described lodgment for traveling pilgrims (eg, hospitality) (Holy crusades)
 - If you got sick in the 11th century it was pretty much a terminal illness for everybody

understandhospice.org/brief-history-hospice/.

Company of the Daughters of Charity of Saint Vincent de Paul

- 17th Century revival
- The Company's mission was to lessen the suffering of the poor
- Their work over the following century redeveloped the concept of hospice as their focus eventually became caring for the sick and dying exclusively with the goal of making patients as comfortable as possible until their last breath





Social worker → Nurse → Physician
Formed St. Christopher's Hospice 1967

"You matter because you are you, and you matter to the end of your life."

"We will do all we can not only to help you die peacefully, but also to live until you die."

Dame Cicely Saunders
Founder of the modern hospice movement

#Cicely100



hospice^{UK}



Dr. Florence Wald

- Dean, Yale School of Nursing
- Sabbatical 1968 at St. Christopher's Hospice
- 1974 – Dr. Wald, 2 pediatricians and a chaplain founded the first hospice in US – Connecticut Hospice
- 1982 – Congress included provision for a Medicare Hospice Benefit

Dr. Josephina Magno (Oncologist)



- Formed American Academy for Hospice and Palliative Medicine
- National Hospice Foundation
- International Hospice Institute

What is the focus of hospice care?

- Hospice care focuses on the pain, symptoms, and stress of serious illness during the terminal phase.
- The terminal phase is defined by Medicare as an individual with a life expectancy of 6 months or less if the disease runs its natural course.
- This care is provided by an interdisciplinary team who provides care encompassing the individual patient and their family's holistic needs.



Who can receive hospice?

- Any individual with a serious illness measured in months not years.
- Hospice enrollment requires the individual has a terminal prognosis.
 - Less than 6 months, as determined by 2 physicians



Medicare Hospice Eligibility

- **Characteristics of end-stage congestive heart disease**

- New York Heart Association (NYHA) Class III if any of the following symptoms are present during less-than-normal activity (ie, patient is comfortable only at rest):
 - Fatigue, palpitations, angina or dyspnea with exercise
- NYHA Class IV as manifested by any of the following symptoms:
 - Dyspnea and/or other symptoms at rest or with minimal exertion, inability to carry out physical activity without dyspnea, and/or other symptoms
 - If physical activity is undertaken, dyspnea, and/or other symptoms worsen
- The patient is being optimally treated for congestive heart failure with diuretics and vasodilators, such as ACE inhibitors, or they are maximally medically managed and have no available surgical options.

- **Comorbid heart disease risk factors**

- Hypertension, diabetes, coronary heart disease, family history of cardiomyopathy, prior myocardial infarction
- Valvular heart disease

www.vitas.com/for-healthcare-professionals/hospice-and-palliative-care-eligibility-guidelines/hospice-eligibility-guidelines/heart-disease.

Figure 10: % of Hospice Decedents by Principal Diagnosis for 2017 & 2018

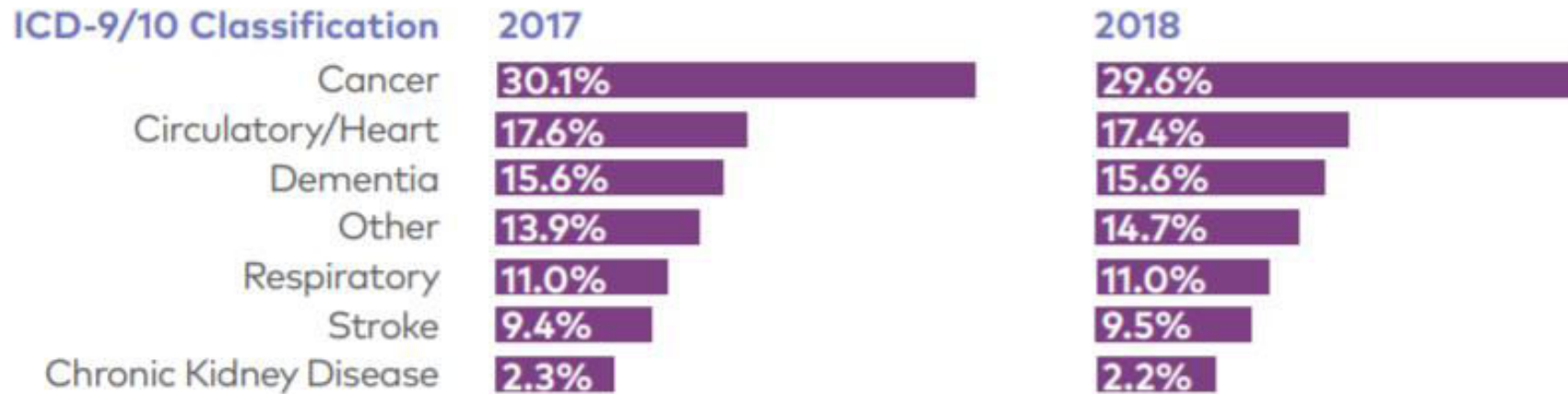
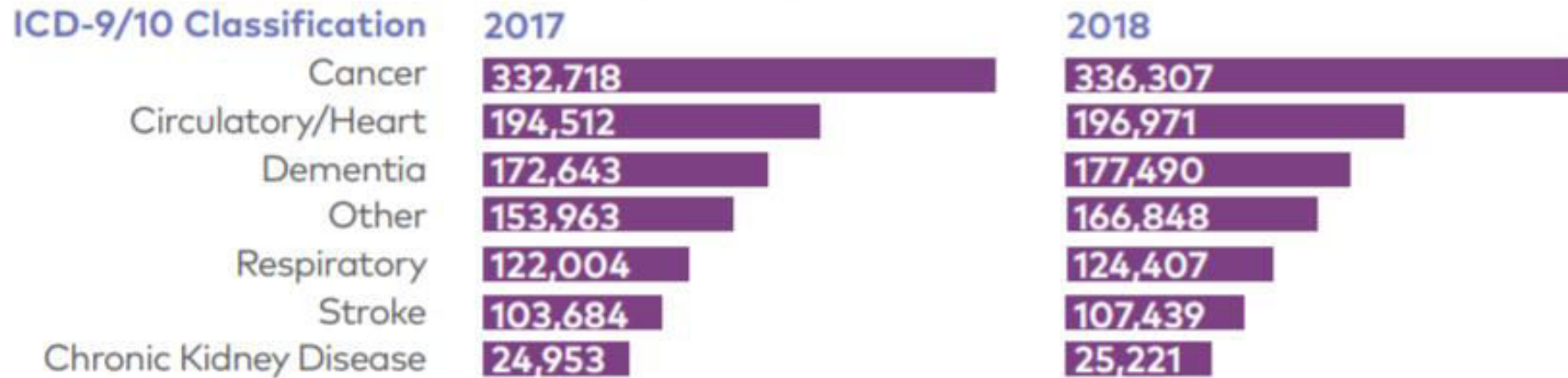


Figure 11: No. of Hospice Decedents by Principal Diagnosis for 2017 & 2018



Can a hospice patient receive curative treatments?

- The goal of hospice is to provide comfort through pain and symptom management, psychosocial and spiritual support because curative treatment modalities are no longer beneficial.
- Hospice should be considered at the point when the burden of any given curative treatment modalities outweighs the benefit coupled with prognosis.
- Other factors to consider and discuss, based on individual patient situations, are treatment modalities that no longer provide benefit due to a loss of efficacy.

www.nhpco.org/wp-content/uploads/2019/04/PalliativeCare_VS_Hospice.pdf



What services are provided?



- 4 levels of care

- Routine
- Inpatient
- Continuous
- Respite care



Where are services provided?

- Home
- Hospice facility
(inpatient or residential)
- Skilled nursing facility
- Long-term care facility
- Assisted living facility
- Hospital
(inpatient levels of care only)
- Group home



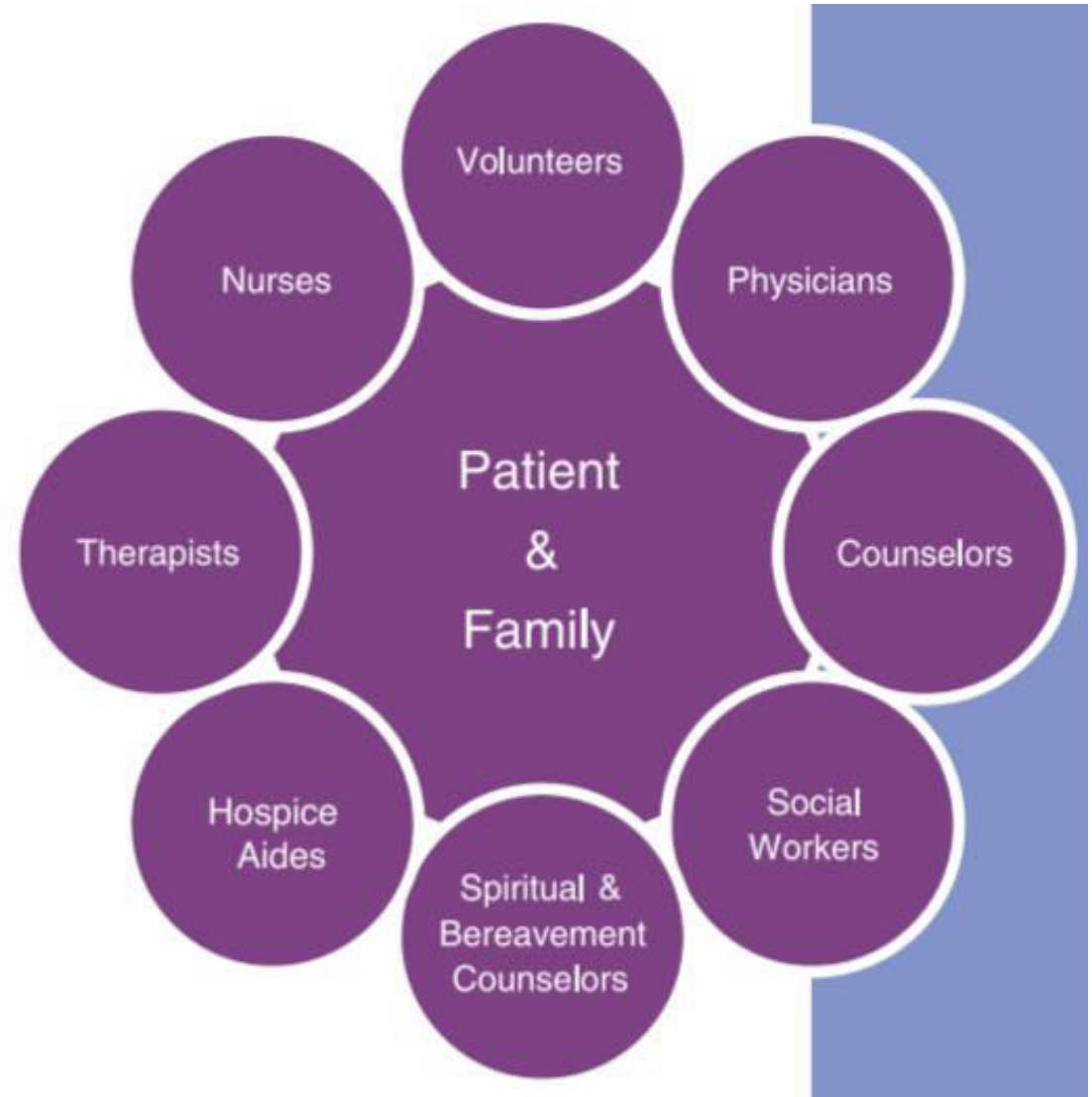
Who pays for hospice care

- Medicare Hospice Benefit
- Medicaid
- Insurance and HMO's
- Private pay
- Philanthropy
- Combination



Who provides these services?

- Physician
- Nurse / APRN / physician assistant
- Social worker
- Chaplain / spiritual and bereavement counselors
- Volunteers
- Hospice aides
- Therapists
- Counselors
- **PHARMACISTS**



How long can an individual receive hospice care?

- As long as the individual meets Medicare, Medicaid, or their private insurer's criteria for hospice care.
- Measured in months, not years.





Self-Assessment!

- Which of the following statements is true regarding the Medicare Hospice Benefit?
 - A. Patients have a prognosis of 6 months or less (if disease follows trajectory)
 - B. Patient forgoes curative therapy, focuses on comfort measures
 - C. If the patient lives longer than 6 months, they are automatically discharged from hospice
 - D. A and B
 - E. All of the above



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 - D. **A and B**
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What is palliative care?

- Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

www.who.int/cancer/palliative/definition/en/.



**Palliative
Care**

Hospice

The SUPPORT Trial

- **Objectives** – To improve end-of-life decision-making and reduce the frequency of a mechanically supported, painful, and prolonged process of dying
- **Design** – a 2-year prospective observational study with 4,301 patients followed by a 2-year controlled clinical trial with 4,804 patients and their physicians randomized by specialty group to the intervention group (n = 2,652) or control group (n=2,152)
- **Setting** – 5 teaching hospitals in the US
- **Patients** – A total of 9,105 adults hospitalized with ≥ 1 of nine life-threatening diagnoses; an overall 6-month mortality rate of 47%

A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators [published correction appears in *JAMA* 1996 Apr 24;275(16):1232]. *JAMA*. 1995;274(20):1591-1598.

The SUPPORT Trial

- **Intervention**

- Physicians in intervention group received:
 - Estimates of the likelihood of 6 month survival for every day up to 6 months
 - Outcomes of CPR resuscitation
 - Functional disability at 2 months
- Specifically trained nurses had multiple contacts with the patient, family, physician and hospital staff to elicit:
 - Preferences
 - Improve understanding of outcomes
 - Encourage attention to pain control
 - Facilitate advance care planning
 - Facilitate patient-physician communication

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The SUPPORT Trial

- **Results**

- Phase I Observation

- Documented

- Shortcomings in communication
 - Frequency of aggressive treatment
 - Characteristics of hospital death

- Findings

- Only 47% of physicians knew when their patients preferred to avoid CPR
 - 46% of do-not-resuscitate (DNR) orders were written within 2 days of death
 - 38% of patients who died spent at least 10 days in an intensive care unit
 - For 50% of conscious patients who died in the hospital, family members reported moderate to severe pain at least half the time

A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators [published correction appears in *JAMA* 1996 Apr 24;275(16):1232]. *JAMA*. 1995;274(20):1591-1598.

The SUPPORT Trial

- **Results**

- Phase II Intervention

- Patients experienced no improvement in patient-physician communication
 - 37% of control patients and 40% of intervention patients discussed CPR preferences
 - No differences in the 5 targeted outcomes
 - Incidence or timing of written DNR orders
 - Physicians' knowledge of their patients' preferences not to be resuscitated
 - Number of days spent in an ICU
 - Receiving mechanical ventilation
 - Comatose before death
 - Level of reported pain
 - No reduced use of hospital resources

A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators [published correction appears in *JAMA* 1996 Apr 24;275(16):1232]. *JAMA*. 1995;274(20):1591-1598.

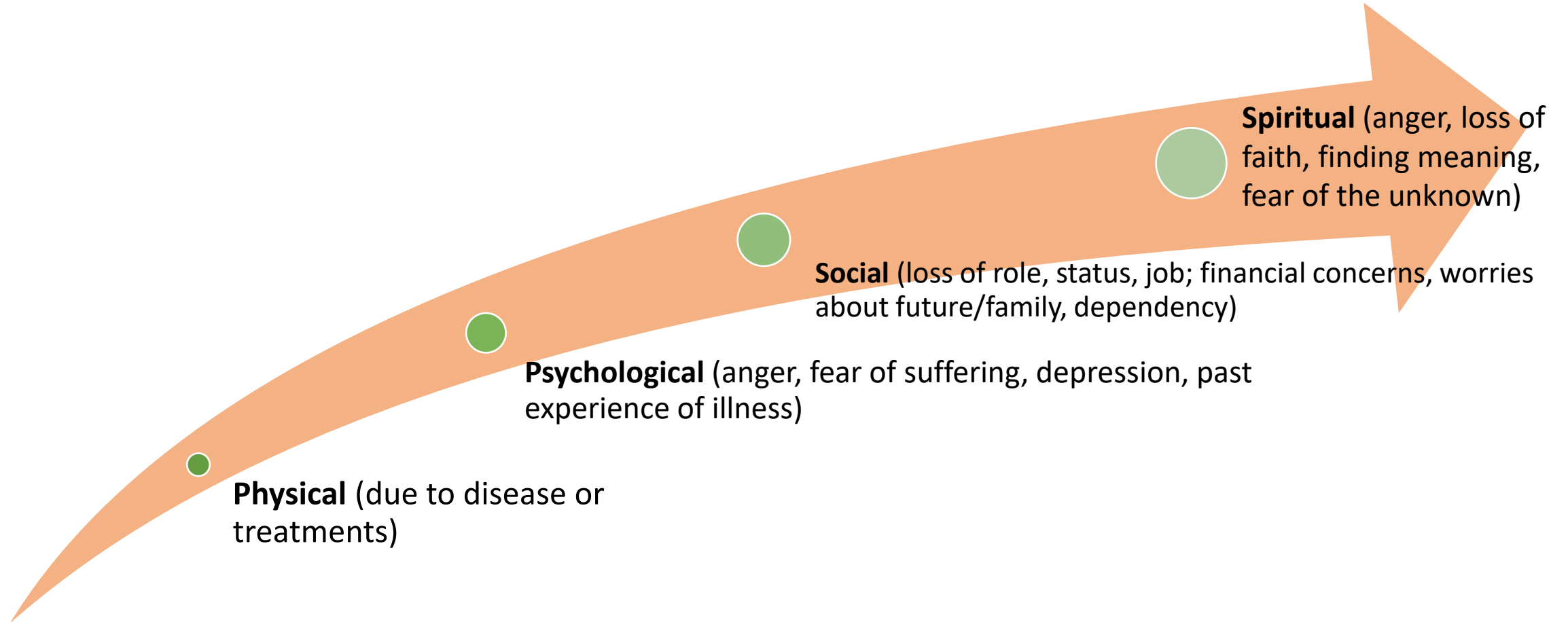
The SUPPORT Trial

- **Conclusions**

- The phase I observation confirmed substantial shortcomings in care for seriously ill hospitalized adults
- Phase II intervention failed to improve care or patient outcomes
- Providing opportunities for more patient-physician communication (advocated as the major method for improving patient outcomes) is inadequate to change established practices
- To improve the experience of seriously ill and dying patients, greater individual and societal commitment and more proactive and forceful measures may be needed

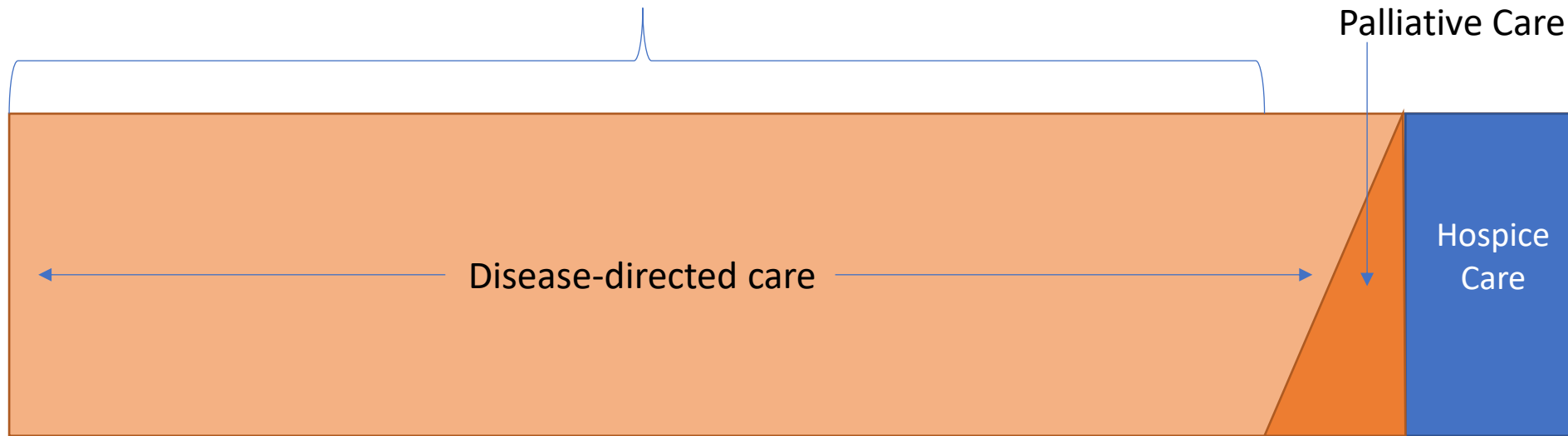
A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). The SUPPORT Principal Investigators [published correction appears in *JAMA* 1996 Apr 24;275(16):1232]. *JAMA*. 1995;274(20):1591-1598.

What is pain? What is total pain?

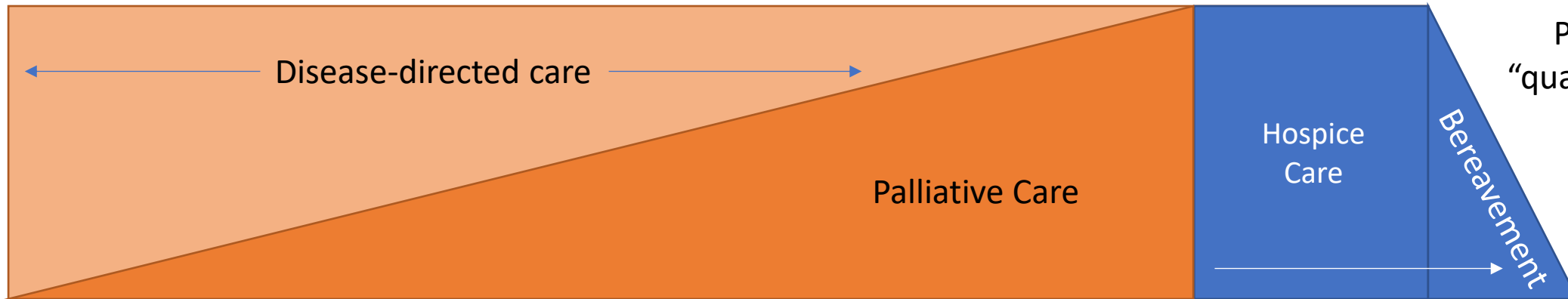


Franklin. Pain and pain management. In: *Textbook of Palliative Care*. 149-177.

Missed opportunities for palliative care



Palliative care as
“brink-of death” care



Palliative care as
“quality-of-life” care

Diagnosis Active therapy Dying Death

Buss. *Mayo Clin Proc.* 2017;92(2):280-286.

Early Palliative Care for NSCLC

- **Background**

- Patients with metastatic NSCLC have a high symptom burden and may receive aggressive care at the EOL
- Purpose of this study was to evaluate introduction of palliative care early after diagnosis on patient-reported outcomes and EOL care in ambulatory patients

- **Methods**

- Patients newly diagnosed with metastatic NSCLC were randomized to receive either palliative care + oncologic care, or standard oncologic care alone
- QOL and mood were assessed at baseline and at 12 weeks

Temel. *N Engl J Med*. 2010;363:733-742.

Early Palliative Care for NSCLC

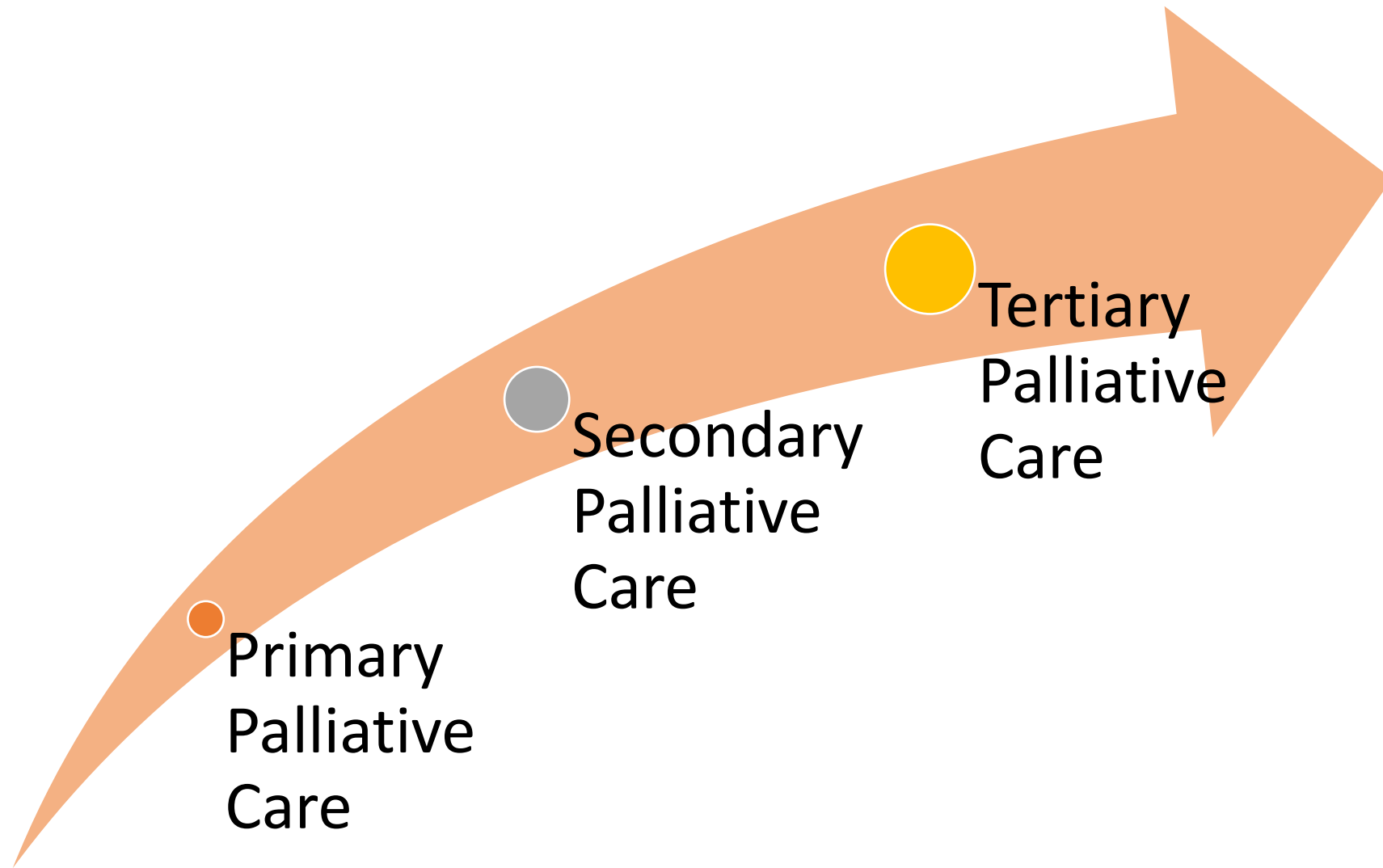
- **Results**

- 151 patients randomized
 - 27 died by 12 weeks
 - 107 completed assessments
- Those in palliative + oncologic care had a better QOL than those receiving just oncologic care
- Fewer patients in the palliative care group had depressive symptoms
- Fewer patients in the early palliative care group received aggressive EOL care
- Median survival was longer among patients receiving early palliative care

- **Conclusion**

- Early palliative care led to significant improvements in QOL and mood
- This cohort had less aggressive care, but longer survival

Temel. *N Engl J Med*. 2010;363:733-742.



Key Components of Hospice and Palliative Care

Buss et al. Understanding palliative care and hospice: a review for primary care providers. *Mayo Clin Proc.* 2017;92(2):280-286.



Symptom Management	Psychosocial/Spiritual support	Decision-Making
<ul style="list-style-type: none">• Pain• Nausea• Delirium• Fatigue and anorexia• Anxiety and depression	<ul style="list-style-type: none">• Counseling• Social work• Pastoral care• Caregiver support• Bereavement	<ul style="list-style-type: none">• Prognostic awareness• Advance care planning• Understanding of outcomes• Defining quality of life• Eliciting values and goals

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