Introduction to Hospice & Palliative Nursing

Optum

Hospice and palliative care are similar but distinct specialties with the goal of relieving suffering. This course examines the origin of hospice and palliative care in addition to providing a view of the day-to-day life of a hospice nurse.

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The Origins of Hospice and Palliative Care

You matter because of who you are, 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

The Founder of Hospice

Dame Cicely Saunders is credited as the founder of hospice. She worked as a British nurse, social worker, and physician and viewed death as a natural part of life. With this perspective, she advocated for specialized care for the dying and created the first hospice, St. Christopher's Hospice in the United Kingdom, in 1967.

Hospice and Palliative Care in the United States

In 1974, the dean of Yale School of Nursing, Florence Wald, founded the first hospice in the United States, Connecticut Hospice in Branford, Connecticut. At that time, hospices were led by volunteers and based in the home. That same year, Dr. Balfour Mount, a surgical oncologist from McGill University, identified palliative care as a specialty, distinguishing it from hospice care. A few years later, in 1983, the Medicare Hospice Benefit was established in the United States with the intent of providing high-quality hospice care to Medicare beneficiaries. On the other hand, palliative care was not recognized as a distinct specialty until 1990 by the World Health Organization. Despite this recognition, organizations were slow to adopt palliative care and it wasn't until 2006 that palliative care became a medical sub-specialty in the United States.



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Established in 1983 with the goal of providing high-quality hospice care to Medicare beneficiaries

The Medicare Hospice Benefit

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Key Points

- Dame Cicely Saunders is credited as the founder of hospice.
- Dr. Balfour Mount, a surgical oncologist from McGill University, identified palliative care as a specialty, distinguishing it from hospice care..
- The Medicare Hospice Benefit was established in 1983 with the intent of providing highquality hospice care to Medicare beneficiaries.

References

1. NEJM Resident 360. Brief history of palliative care. November 20, 2020. Available at: https://resident360.nejm.org/content_items/history-of-palliative-care. Accessed February 9, 2022.

2. NPCO. History of hospice. 2021. Available at: https://www.nhpco.org/hospice-care-overview/history-of-hospice/. Accessed February 9, 2022.

Defining Hospice and Palliative Care

Similar but Distinct Specialties

Hospice and palliative care are similar but distinct specialties.

Palliative care is specialized care for individuals living with serious illness, such as heart failure or cancer, that provides interventions to prevent or manage symptoms of the underlying disease process while the patient is still receiving curative care for that illness.

Hospice care is a type of palliative care provided to those with a serious illness when curative interventions can no longer control the disease or are not desired by the individual. The goal of hospice care is to prevent and manage symptoms of the serious illness while neither hastening nor postponing death.

	Palliative Care	Hospice Care
Distinguishing	Care is provided and services are coordinated by an interdisciplinary team	Care is provided and services are coordinated by an interdisciplinary team
Characteristics of Palliative & Hospice Care	Patients, families, and palliative as well as non- palliative health care providers establish the plan of care	Patients, families, and only palliative health care providers establish the plan of care
	Services are available concurrently with curative care	Services are available to individuals with a prognosis of 6 months or less

Palliative care is specialized symptom management care for individuals living with serious illness while still receiving curative care for that illness. Hospice care is a type of symptom management care provided to those with a serious illness when curative interventions can no longer control the disease or are not desired by the individual.



Key Points

- Palliative care is specialized care for individuals living with serious illness to prevent or manage symptoms of the underlying disease process while still receiving curative care for that illness.
- Hospice is a type of palliative care provided to those with a serious illness when curative interventions can no longer control the disease or are not desired by the individual with the intent of preventing and managing symptoms of the serious illness while neither hastening nor postponing death.

References

- 1. Centers for Medicare & Medicaid Services (CMS). Medicare and Medicaid Programs: Hospice Conditions of Participation; Final Rule. Fed Regist. 2008;73(109):32088-32220. Codified at 42 CFR 418. Available at: https://ecfr.io/Title-42/pt42.3.418#se42.3.418_12. Accessed February 9, 2022.
- 2. National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. https://www.nationalcoalitionhpc.org/ncp. Accessed February 9, 2022.

Lesson 3 of 10

Guidelines for Quality Hospice and Palliative Care



Guidelines for Quality Hospice Care

Guidelines for quality hospice care were established by the Medicare Hospice Benefit and are detailed in The Code of Federal Regulations, Title §42, Chapter 4, Part §418. These regulations describe who is eligible for hospice while guiding the delivery of patient care and establishing requirements for payment of services. All hospice nurses providing hospice care should be familiar with the six subparts of The Code of Federal Regulations as they serve as the foundation of quality hospice care. The six subparts of The Code of Federal Regulations are:

- Subpart A General Provisions and Definitions
- Subpart B Eligibility, Election and Duration of Benefits
- Subpart C Conditions of Participation: Patient Care
- Subpart D Conditions of Participation: Organizational Environment
- Subpart F Covered Services
- Subpart H Coinsurance



Guidelines for Quality Palliative Care

Guidelines for quality palliative care were established by the National Coalition for Hospice and Palliative Care so individuals with serious illness who were not hospice-eligible could still receive the care necessary to palliate symptoms. These guidelines are titled the National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care and are now in the 4th edition. All nurses providing palliative and hospice care should be familiar with the eight domains of quality palliative care. The eight domains of palliative care are:

- Domain 1: Structure and Process of Care
- Domain 2: Physical Aspects of Care
- Domain 3: Psychological and Psychiatric Aspects of Care
- Domain 4: Social Aspects of Care
- Domain 5: Spiritual, Religious, and Existential Aspects of Care
- Domain 6: Cultural Aspects of Care
- Domain 7: Care of the Patient Nearing the End of Life
- Domain 8: Ethical and Legal Aspects of Care

nal Consensus Project's Clinical Practice Guidelines for Quality Palliative de which of the following domains of care? (select all that apply)
Physical Aspects of Care
Cultural Aspects of Care
Spiritual, Religious, and Existential Aspects of Care
Psychological and Psychiatric Aspects of Care



Key Points

- Guidelines for quality hospice care were established by the Medicare Hospice Benefit and are detailed in The Code of Federal Regulations, Title §42, Chapter 4, Part §418.
- Guidelines for quality palliative care were established by the National Coalition for Hospice and Palliative Care and are titled the National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care.

References

- Centers for Medicare & Medicaid Services (CMS). Medicare and Medicaid Programs: Hospice Conditions of Participation; Final Rule. Fed Regist. 2008;73(109):32088-32220. Codified at 42 CFR 418. Available at: https://ecfr.io/Title-42/pt42.3.418#se42.3.418_12. Accessed February 9, 2022.
- 2. National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. https://www.nationalcoalitionhpc.org/ncp. Accessed February 9, 2022.

Sizing Up Hospice Care

Beneficiary Enrollment

Most hospice patients receive hospice care through the Medicare Hospice Benefit. Medicare beneficiaries can enroll in hospice care if they are certified as terminally ill based on the clinical judgement of the patient's attending physician and the hospice physician. In 2020, 1.72 million Medicare beneficiaries were enrolled in hospice care. This represents a 6.8% increase in beneficiary enrollment from the prior year.



Medicare Beneficiary Enrollment

Year

A. 2016 | **1.43**

B. 2017 | 1.49
C. 2018 | 1.55
D. 2019 | 1.61
E. 2020 | 1.72

Medicare hospice beneficiary enrollment has increased year after year since 2016.

Beneficiary Discharge

Of those enrolled in hospice care in 2020, 15.4% of the hospice discharges were discharged alive.

Reason for Live Discharge



The majority of beneficiary discharges from hospice care in 2020, 84.6%, were due to patient death.

Principal Hospice Diagnosis

The principal hospice diagnosis is the diagnosis most likely related to the patient's terminal prognosis. In 2020, Alzheimer's/Dementia/Parkinson's was the most common principal diagnosis.



Principal Hospice Diagnosis

Principal Diagnosis

- A. Alzheimers Dementia Parkinsons | 18.5
- B. Circulatory Heart | 9.3
- C. Cancer | 7.5
- D. Respiratory | 6
- E. Stoke CVA | 5
- F. Kidney Disease | 1.5
- G. Severe Malnutrition | 1.3
- H. COVID-19 | 0.9

In 2020, Alzheimer's/Dementia/Parkinson's was the leading principal diagnosis.

Location of Care

Most individuals express the desire to die in their own home rather than a traditional health care setting, such as a nursing facility or assisted living facility. Data from 2020 indicates that Medicare beneficiaries received the most days of care at private residences followed by nursing facilities and then then assisted living facilities.

Examining average days by location of care demonstrates that beneficiaries living within assisted living facilities have the longest length of stay followed by nursing facilities and then private residences.



Average Days by Location of Care

Location

- A. Private Residence | 90
- B. Nursing Facility | 133
- C. Assisted Living Facility | **172**

In 2020, beneficiaries received the most days of care at private residences.

Length of Stay

Short lengths of stay can reduce the quality of hospice care delivered by interdisciplinary team. In 2020, the average length of stay was 97.0 days, which was the largest increase in average of stay over the past five years. The median length of service has remained around 18 days for more than a decade.

Length of Stay



In 2020, 50% of beneficiaries were enrolled in hospice care for 18 days or less.

How many Medicare beneficiaries received hospice in 2020?

1.72 million

What was the leading principal diagnosis (primary hospice diagnosis) in 2020?

Alzheimer's, Dementia, Parkinson's What was the median length of hospice service in 2020 and for the past decade?

18 days

Key Points

- Medicare hospice beneficiary enrollment has increased year after year since 2016.
- In 2020, Alzheimer's/Dementia/Parkinson's was the leading principal diagnosis.
- Although short lengths of stay can reduce the quality of hospice care delivered by interdisciplinary team, 50% of beneficiaries were enrolled in hospice care for 18 days or less in 2020

References

1. Centers for Medicare & Medicaid Services (CMS). Medicare and Medicaid Programs: Hospice Conditions of Participation; Final Rule. Fed Regist. 2008;73(109):32088-32220. Codified at 42 CFR 418. Available at: https://ecfr.io/Title-42/pt42.3.418#se42.3.418_12. Accessed February 9, 2023. 2. National Hospice and Palliative Care Organization. 2022. NHPCO Facts and Figures: 2022 Edition. Available at: https://www.nhpco.org/hospice-care-overview/hospice-facts-figures . Accessed February 9, 2023.

Payment for Hospice Care

Hospices are paid a daily rate for each day the beneficiary is enrolled in hospice; payment is made regardless of the cost of services provided on a given day and on days when no services are provided. Payments are made based on a fee schedule that encompasses four levels of service.

Payment Based on Level of Service

There are four levels of hospice service designed to meet the symptom management needs of the patient. Each level of service has a different payment; the payment reflects the variation in costs in providing each level of care. The four levels are service are:

- Routine Home Care
- Continuous Home Care
- General Inpatient Care
- Inpatient Respite Care

ROUTINE HOME	CONTINUOUS HOME	GENERAL INPATIENT	INPATIENT RESPITE
CARE	CARE	CARE	CARE

The standard level of home care

- Hospices receive a higher daily rate for routine home care on days 1-60. The daily rate for FY 2022 is \$203.81.
- Payment is reduced for day 61 and thereafter. et go of expectation. The reduced daily rate for FY 2022 is \$161.02
- Hospices can receive an additional payment called the service intensity add-on (SIA) if services are provided in the last 7 days of life. The SIA payment for FY 2022, up to 4 hours, is \$61.07 per hour.



ROUTINE HOME CARE	CONTINUOUS HOME CARE	GENERAL INPATIENT CARE	INPATIENT RESPITE CARE
General inpatient care is	provided in an inpatient facilit	y with the goal of managing ur	controlled symptoms.

ROUTINE HOME CARE	CONTINUOUS HOME CARE	GENERAL INPATIENT CARE	INPATIENT RESPITI CARE
Innationt recruite care is	provided in a facility for up to f	we days with the goal of giving	the primary caregiver a
break.		ive days with the goal of giving	, the primary caregiver a
• The FY 2022 daily	rate for inpatient respite care	is \$474.43.	

Match the level of service to its description.

SUBMIT

Level of Service Utilization

Although hospices must offer all four levels of service, the majority of hospice patients receive routine home care level of service. In 2018, 98% of hospice patients received this level of service.



Level of Service Utilization

Key Points

- Hospices are paid a daily rate for each day the beneficiary is enrolled in hospice; payment is made regardless of the cost of services provided on a given day and on days when no services are provided.
- Payments are made based on a fee schedule that encompasses four levels of service routine home care, continuous home care, general inpatient care, and inpatient respite care.
- Although hospices must offer all four levels of service, the majority of hospice patients receive routine home care level of service.

References

- 1. Centers for Medicare & Medicaid Services (CMS). Medicare and Medicaid Programs: Hospice Conditions of Participation; Final Rule. Fed Regist. 2008;73(109):32088-32220. Codified at 42 CFR 418. Available at: https://ecfr.io/Title-42/pt42.3.418#se42.3.418_12. Accessed February 9, 2022.
- 2. Centers for Medicare & Medicaid Services (CMS). Update to hospice payment rates, hospice cap, hospice wage index and hospice pricer for FY 2022. Available at: www.cms.gov/files/document/mm12354.pdf. Accessed May 23, 2022.
- 3. National Hospice and Palliative Care Organization. 2020. NHPCO Facts and Figures: 2020 Edition. Available at: www.nhpco.org/hospice-facts-figures/ . Accessed February 9, 2022.

Lesson 6 of 10

Hospice Nurse Roles



The Role of the Nurse in Relieving Human Suffering

Historically, nurses have played an important role in relieving human suffering by:

- Protecting, promoting, and optimizing health
- Advocating for individuals and populations
- Preventing illness and injury.

Hospice nurses are no exception. The primary focus of a hospice nurse is palliating symptoms of advanced disease and relieving suffering of the dying. Although the focus of the hospice nurse is relief of human suffering, not all hospice nurses have the same responsibilities. The work of a hospice nurse is broken up into various roles.

The Various Roles of the Hospice Nurse

Admission Nurse

Identifies the hospice appropriate patient and guides eligible patients through the hospice admission process

Identifies the Hospice Appropriate Patient

- Reviews hospice referral information including a recent history and physical and any available lab work
- Identifies payor source
- Assesses patient, caregiver and home
- Reviews referral and current assessment with hospice medical director to determine hospice appropriateness

Guides Eligible Patients Through the Hospice Admission Process

- Reviews the hospice election statement
- Initiates the plan of care and provides any necessary patient or family education until patient can be seen by the primary nurse
- Orders new medications from the pharmacy; provides patient and family education on medication administration
- Orders durable medical equipment (DME)
- Notifies the RN case manager, hospice aid, social worker, and spiritual counselor of the new admission; may schedule visits with the on-call nurse, if needed

Case Manager

The case manager is a Registered Nurse responsible for coordinating the care of the hospice patient through regular visits and communication with the interdisciplinary team

- Works closely with the physician, social worker, spiritual counselor, home health aide, volunteers and other nurses to provide physical, emotional, and spiritual care to the patient and family
- Assigned a caseload that may vary by daily census and current staffing levels; the average caseload is 11.2 patients per RN case manager

Regular Visits

- Routine, symptom management, and death visits as well as home health aide supervisory visits
- Visit frequency varies from daily to once every two weeks depending on patient wishes, symptom management needs, and level of care
- The case manager sets a visit schedule at the beginning of each week, and this is adjusted based on changes in patient condition and/or on-call visits
- At each visit, the CM will
 - Perform a comprehensive assessment
 - Ensure the plan of care is achieving symptom control; if symptoms are poorly managed, the plan of care is adjusted
 - Review medications, including counting and ordering medications if supply is low
 - Evaluate home safety and DME use

Communication with the Interdisciplinary Team

- Attend weekly interdisciplinary team meetings to review current status of the patient and discuss any symptom management needs
- Collaborate with interdisciplinary team members after visit to coordinate care
- Present recertification information

Visit Nurse

Either a Registered Nurse or Licensed Practical Nurse that provides supplemental visits in addition to the visits made by the RN Case Manager

Triage Nurse

Provides telephonic guidance to patients and caregivers during symptom crises and determines whether an in-person visit is necessary

- Available to take phone calls from patients and families
 - Usually available outside of normal business hours (evenings and weekends)
- Provide symptom management guidance
 - May instruct the family member to administer a medication or provide a non-pharmacologic intervention
 - If the symptom can not be controlled, the triage nurse will request an in-person visit from the oncall nurse

On-Call Nurse

Responsible for providing patient care outside of normal business hours (evening and weekends)

- Can be a dedicated position or the Case Managers will cover these hours through a rotation schedule
- Visits are usually determined by the triage nurse

Inpatient Unit Nurse

Provides direct patient care to individuals admitted to the inpatient unit for symptom management

- Works 8- or 12-hour shifts
- Caseload will vary by organization, but one nurse usually cares for 5 or 6 patients at a time
- Palliation of symptoms is still the goal
- The IPU is designed to mimic a home environment and family members are usually permitted to stay around the clock

Nurse Manager

Nurse responsible for overseeing the day-to-day activities of the nursing staff

This nurse identifies the hospice appropriate patient and guides eligible patients through the hospice admission process

Admission Nurse



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• The work of a hospice nurse is broken up into various roles, including admission nurse, case manager, visit nurse, triage nurse, on-call nurse, inpatient unit nurse, and nurse manager.

References

- Centers for Medicare & Medicaid Services (CMS). Medicare and Medicaid Programs: Hospice Conditions of Participation; Final Rule. Fed Regist. 2008;73(109):32088-32220. Codified at 42 CFR 418. Available at: https://ecfr.io/Title-42/pt42.3.418#se42.3.418_12. Accessed February 9, 2022.
- 2. National Hospice and Palliative Care Organization. 2020. NHPCO Facts and Figures: 2020 Edition. Available at: www.nhpco.org/hospice-facts-figures/ . Accessed February 9, 2022.
- 3. National Hospice and Palliative Care Organization. 2016. Staffing Guidelines for Hospice Home Care Teams.

Lesson 7 of 10

Demographics of the Hospice Nurse

Hospice Nursing in the United States

There are an estimated 1, 553, 518 hospice Registered Nurses in the US. Let's take a closer look at the demographics of these nurses.

Hospice Registered Nurses by Gender

Percentage of Hospice Registered Nurses by Gender



Most hospice Registered Nurses, 90%, are female.

Age of Hospice Registered Nurse

Most hospice Registered Nurses, 61%, are aged more than 40 years.

Percentage of Hospice Registered Nurses by Age



Most hospice Registered Nurses, 61%, are aged more than 40 years.

Education Level of Hospice Registered Nurses

The most common degree of a hospice Registered Nurse is an Associate Degree (43%) followed closely by a Bachelor's Degree (40%).

Percentage of Hospice Registered Nurses by Education Level





The most common degree of a hospice Registered Nurse is an Associate Degree (43%) followed closely by a Bachelor's Degree (40%).

Certifications Held by Hospice Registered Nurses

Hospice is a specialty and certification demonstrates mastery of this specialty. The majority of hospice nurses do not hold a certification in hospice or palliative nursing.



Percentage of Hospice Nurses with a Certification

	Certified

The majority of hospice nurses do not hold a certification in hospice or palliative nursing.





Key Points

• There are an estimated 1,553,518 hospice Registered Nurses in the US.

- The majority, 89.8%, of hospice Registered Nurses are female and aged more than 40 years (61%).
- The most common degree of a hospice Registered Nurse is an Associate Degree (43%) followed closely by a Bachelor's Degree (40%).

References

- U.S. Department of Health and Human Services, Health Resources and Services Administration (2010). The Registered Nurse Population: Findings from the 2008 National Sample Survey of Registered Nurses. Available at: The Registered Nurse Population (September 2010) (hrsa.gov). Accessed February 9, 2022.
- 2. Zippia. Hospice registered nurse demographics and statistics in the US. 2022. Available at: www.zippia. com. Accessed May 20, 2022.

Summary

Key Points

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Hospice and palliative care are similar but distinct specialties with the goal of relieving suffering.

Hospice and palliative nursing is a relatively new specialty. Dame Cicely Saunders is credited as the founder of hospice while Dr. Balfour Mount, a surgical oncologist from McGill University, identified palliative care as a specialty, distinguishing it from hospice care.

Palliative care is specialized care for individuals living with serious illness to prevent or manage symptoms of the underlying disease process while still receiving curative care for that illness.

Hospice is a type of palliative care provided to those with a serious illness when curative interventions can no longer control the disease or are not desired by the individual with the intent of preventing and managing symptoms of the serious illness while neither hastening nor postponing death.

Hospice nurse responsibilities focus on achieving a common goal – relieving the suffering of the dying patient using evidence-based palliative care techniques

Thank you for completing this course!

Lesson 9 of 10

Knowledge Assessment

Now is your time to demonstrate your knowledge. This quiz will ask five questions. You will need a score of 80% or higher to pass.

1. Who is considered the founder of the modern hospice movement?

O Dame Cicely Saunders

🔵 The Medicare Hospice Benefit

Dr. Balfour Mount

🔵 Florence Wald

Lesson 10 of 10

Quiz

Now is your time to demonstrate your knowledge. This quiz will ask five questions. You will need a score of 80% or higher to pass.

01/05

Who is considered the founder of the modern hospice movement?

\bigcirc	Dame Cicely Saunders
\bigcirc	The Medicare Hospice Benefit
\bigcirc	Dr. Balfour Mount
\bigcirc	Florence Wald

02/05

Which of the following statements is true regarding the role of the hospice nurse? (select all that apply)

The inpatient unit (IPU) nurse provides direct care to patients in the home setting
The triage nurse provides guidance to IPU nurses
The admission nurse identifies the hospice appropriate patient and guides eligible patients through the hospice admission process
The case manager oversees the day-to-day activities of the nursing staff

03/05

Palliative care is specialized care for individuals living with serious illness to prevent or manage symptoms of the underlying disease process while still receiving curative care for that illness.

TrueFalse

04/05

 \bigcirc

Which of the following is true regarding hospice care?

Hospice postpones death

\bigcirc	Hospice is a type of curative care
\bigcirc	Hospice is provided to those with serious illness when curative interventions can no longer control the disease
\bigcirc	Hospice hastens death

05/05

Hospice nurse responsibilities focus on achieving a common goal – relieving the suffering of the dying patient using evidence-based palliative care techniques.

TrueFalse