

Hospice: Leading Interdisciplinary Care

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Hospice: Leading Interdisciplinary Care

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In 1967, Dame Cicely Saunders founded St. Christopher's Hospice in south west London. It is now one of many but is still the leader in the field. It was her personal achievement and has been imitated all over the world.

St. Christopher's was the first modern hospice, although there were a number of homes in existence for the dying, most of which were run by religious orders.

Ms. Saunders raised the funds for the hospice and contributed some of her own money. She introduced the idea of "total pain" which included the physical, emotional, social, and spiritual dimensions of distress. She regarded each person, whether patient or staff, as an individual to the end¹.

¹ British Medical Journal, 2005. <https://www.bmj.com/content/suppl/2005/07/18/331.7509.DC1>

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Executive Summary

The Medicare hospice benefit is unique and has numerous attributes; many of which are not universally understood. Dobson | DaVanzo was commissioned by the National Hospice and Palliative Care Organization (NHPCO) to develop a policy brief on hospice care that could serve as a concise single source document highlighting key aspects of past – present – and future hospice care and its operations. This document is intended to be widely distributed to stakeholders and policymakers as they consider how to best integrate the hospice program into a rapidly changing health care system while preserving its essential and unique character.

Today, value across the health care system in large part involves diverse clinical disciplines to coordinate care, while reducing overall costs without compromising patient outcomes. For decades, the hospice program includes terminally ill patients and their families to collaboratively develop care plans with their hospice interdisciplinary team and take control of patients' end of life care.

The hospice value proposition brings care to patients and their families that is unique and meaningful, as it provides comfort care as well as physical, emotional, and spiritual support to patients and their families on terms that they themselves choose. Hospice provides each family services that are tailored to their preferences and the patient's clinical condition.

Executive Summary

Dimensions of the Hospice Value Proposition

Hospice: The first patient care system in the U.S. to employ comprehensive person and family-centered care

- Medicare benefit established in 1982 with bipartisan Congressional support
- Care is available to patients and their families seven days a week, 24 hours a day
- Hospice care closely integrates inpatient care and home care to ensure coordination and continuity
- The patients, their families, and anyone essential to the patients' life create the "unit of care"
- Volunteers are crucial to the success of the hospice care model
- Palliative and supportive care is directed at ameliorating the physical, emotional and spiritual discomfort associated with terminal illness
- Anticipatory grief counseling is available for the patient and his or her family before death. Bereavement services are available for the family after the patient has died, including phone calls, follow-up visits and support.

Hospice Works...

- Because it is a unique and multi-dimensional benefit that integrates person-centered interdisciplinary approaches resulting in high patient and family satisfaction
- Because the hospice team works closely with the patient and their family to honor the patient's preferences and wishes and enables and encourages families to remain closely involved in the care of the patient and provides support and education for the patient and family concerning death and dying
- Because it allows for the patient's and families' choice of setting, most often in whatever setting the patient calls home
- Because the Medicare payment system "bundles" payment to facilitate program savings

Preserving the Hospice Value Proposition Will Require Policies That:

- Preserve the integrity of the hospice benefit as Medicare Advantage (MA) plans, ACOs and other organizational delivery forms as they expand in coming years
- Concurrently coordinate the hospice benefit with medical and psychological care under all Medicare payment models
- Expand timely access to hospice and palliative care based on the individual's unique care needs
- Ensure high-quality supply of hospice care providers and professionals who are poised to address the rapidly aging population seeking hospice and palliative care

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Hospice Works...

Hospice works because it is a unique and multi-dimensional benefit that leverages person-centered interdisciplinary care resulting in high patient and family satisfaction.

Hospice care combines interdisciplinary approaches with the care provided by the hospice team and family and friends. The integrated care team works with patients' families who are the main source of care for the patient. Patients can choose to receive hospice services in many settings, often choosing to receive care in their homes rather than in a facility (e.g. a hospital, nursing home). Hospice providers involve the family throughout the duration of care, while providing family members respite as needed. The involvement of family and friends in end of life care has been shown to be of high value to many terminally ill patients. It supports invaluable time spent together and allows for both the patient and the family to adjust to the new reality of losing a loved one. Hospice care fulfills the unique needs of terminally ill patients that curative treatment is generally not able to provide with physical and emotional support throughout the duration of care.

Hospice works because it allows the patients' and families' choice of setting, most often the home—the hospice team works closely with the patient and their family to honor the patient's preferences and wishes and enables and encourages families to remain closely involved in the care of the patient.

Patients receiving hospice services may do so in a variety of locations based on their situation, needs, and preferences. While the patient's home is the most common setting for hospice care, patients may also receive hospice care at an assisted living facility, a nursing home, a residential hospice facility, or any other location the patient calls home. For complex care and symptom management needs that cannot be addressed in the home setting, short-term inpatient care can also be provided in a hospice inpatient facility, hospital, or skilled nursing facility. Hospice services can be provided wherever the patient and family feel most comfortable and individualized care planning allows for changes in the location of care based on the patient's needs. Caregiver education, support and assistance is available to family members who will be working closely with the care team.

Hospice works because the Medicare payment system "bundles" payment in order to facilitate program savings – hospice savings are well-documented.

Hospice care under the Medicare program aims to prevent pain and suffering for the terminally ill, through medical, non-medical interventions, and comfort care. To elect hospice care under Medicare, a patient must agree to forgo curative medical treatment for his or her terminal illness and related conditions. The Medicare payment model for hospice is comprised of an all-inclusive per diem payment to the hospice provider, who then manages the entire interdisciplinary team under the bundled payment. This payment is meant to cover visits by

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any hospice professional as well as ancillary services, such as: on-call services, medical equipment, and medications related to the terminal prognosis.

The four levels of hospice care include:

- 1) routine home care
- 2) continuous home care
- 3) inpatient respite care, and
- 4) general inpatient care

Each level of care has its own per diem payment rate. The hospice Medicare payment was designed to ensure patients are provided with the appropriate intensity of care for their individual needs without receiving unnecessary services.

Several studies have demonstrated that hospice care results in substantive cost savings to the Medicare program.^{2,3} Patients in hospice care do not receive procedures, treatments, or tests solely meant to prolong life as related to the terminal illness. These types of services can drive up the cost of caring for a terminally ill patient. For instance, a study by Powers et al. indicates that longer durations of hospice care use and higher percentages of hospice users in the Medicare population equate to greater savings for the Medicare program. As an example, if 80 percent (as opposed to the current 50 percent) of decedent Medicare beneficiaries used hospice for 24 months, nearly \$2 billion could be saved by the Medicare program annually.⁴

Currently, providers, payers, and policymakers are placing enormous value on the hospice care delivery model by recognizing the value of hospice as a bundled payment model as well as honoring patient and family preferences. Specifically, the Centers for Medicare & Medicaid Services' (CMS) Innovation Center (CMMI) is testing the Medicare Care Choice Model (MCCM) which recognizes the value of hospices being able to offer support to a patient and families without requiring them to elect the hospice benefit until the patient and family are ready, through their experience with MCCM or at any time.

Furthermore, in early 2018, CMS released a new interpretation of "primarily health related" pertaining to Medicare Advantage (MA) Plans to develop supplemental benefits for the chronically ill. Within the same month, Congress passed the Bipartisan Budget Act of 2018 to further appreciate the need for supplemental benefits for Medicare Advantage enrollees - recognizing the value of supplemental services for patients and families.

² Taylor Jr. et al. What length of hospice use maximizes reduction in medical expenditures near death in the US Medicare program? June 2007. *Social Science & Medicine* 65 (2007): 1466-1478.

³ Kerr et al. Cost Savings and Enhanced Hospice Enrollment with a Home-Based Palliative Care Program Implemented as a Hospice-Private Payer Partnership. *J Palliative Med*, 2014; 17(12).

⁴ Powers et al. Cost Savings Associated with Expanded Hospice Use in Medicare. *J Palliative Med*. 2015 May 1; 18(5):400-401.

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Finally, in 2018, the Physician-Focused Payment Model Technical Advisory Committee also emphasized to Secretary Alex Azar at the Department of Health and Human Services (HHS) a model to address the seriously ill population is of the “highest possible priority”.

The Innovation Center continues to emphasize the value of hospice by announcing that the CY 2021 Medicare Advantage Value Based Insurance Design (VBID) model would include the hospice benefit and actively seeks stakeholder engagement and expertise.

Purpose and Context

The Hospice Value Proposition

Hospice is widely recognized as being the first healthcare program to integrate palliative and supportive care for terminally ill patients at the end of their lives. For more than 50 years, hospice care has allowed these patients to die with dignity, compassion, and respect. Since the first U.S. hospice began operations in 1974, more than 4,500 hospices have joined the Medicare program. Medicaid and most private payers also support hospice services.⁵

The hospice benefit is unique in that the patient **and** family comprise the “unit of care.” Throughout a patient’s time in hospice care, the family receives support through direct caregiving, social work services, spiritual support, bereavement counseling, and ongoing communication with the interdisciplinary care team. The patient receives an array of services based on the development of a care plan by the hospice, in collaboration with the patient and family, which can include physician and nursing services to ensure that medical needs are met and that he or she is comfortable, aide services to assist with personal care, physical therapy, occupational therapy or speech language pathology, massage, music and art therapy, and counseling and support to fashion his or her own personal end of life experience. The inter-disciplinary care team is charged with addressing the patient’s physical, mental, and spiritual wellbeing; fear, anxiety, bewilderment, and loneliness are addressed as shown in Figure 1, which is Dame Saunders’ original schematic representation of hospice care.

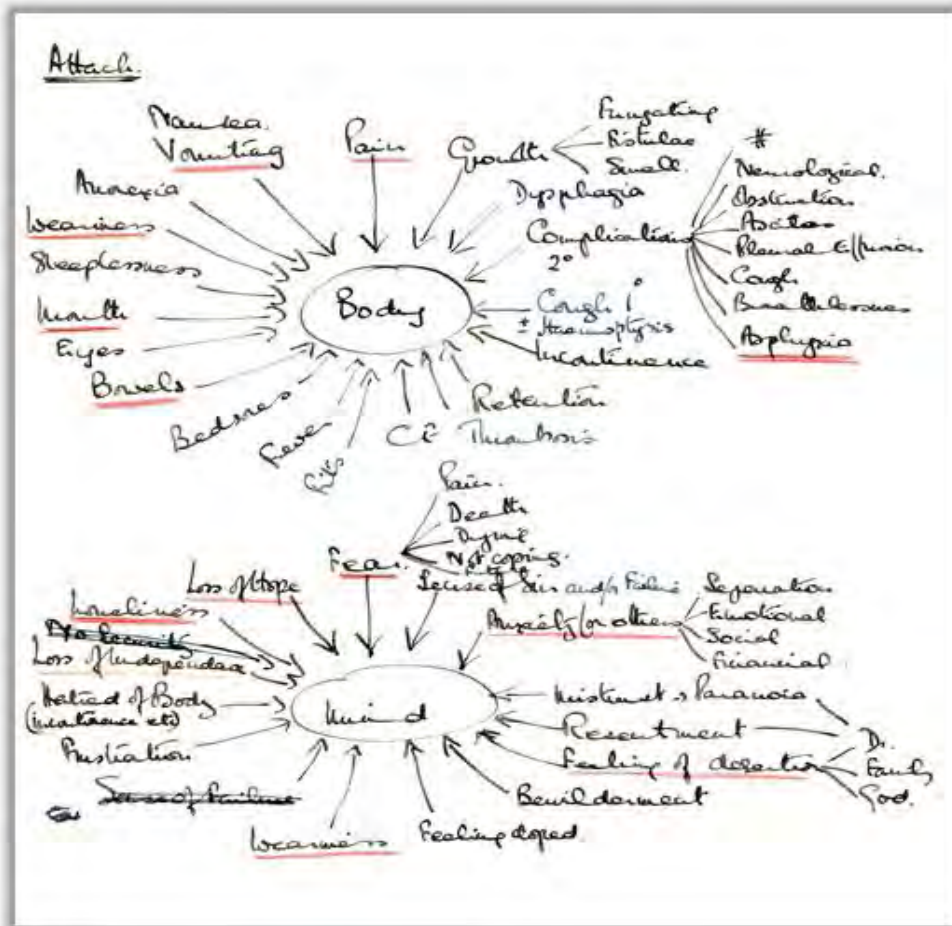
Care coordination is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services.

—Agency for Healthcare Research and Quality

⁵ National Hospice and Palliative Care Organization. Facts and Figures: Hospice Care in America. 2017 Edition (Revised April 2018). https://www.nhpco.org/sites/default/files/public/Statistics_Research/2017_Facts_Figures.pdf

Purpose and Context

Figure 1: Dame Saunders' Original Concept of Hospice Care



Physicians and nurses, physical, and occupational therapists, speech language pathologists, hospice aides, grief counselors, social workers, chaplains, volunteers, and any other discipline identified as a part of the patient's care plan are made available to patients and their families. The hospice interdisciplinary team works to address all components of the patient and family's care, to provide training and support to the family caregivers, and to describe what will happen during their time in hospice care prior to death. Care is also provided after the patient's death with bereavement support for family members through follow up phone calls, individual and group counseling through the first anniversary of the patient's death.

Purpose and Context

For the past four decades, long before the current health care system's transition to coordinated care and value-based payment,⁶ hospice has been coordinating care among different clinical disciplines, providers and caregivers to deliver an integrated program of supportive and palliative care to the dying. Hospice is the only care modality in which the focus is to care for both the patient and the family. In fact, hospice care is often referred to as one of the nation's first "coordinated care" programs.⁷ Care is person-centered, with patients' wishes being respected.

Its proponents point out that in addition to its widely recognized clinical benefits, hospice care's potential for cost savings stems from two factors: 1) the U.S. hospice model emphasizes end-of-life care at home and treatments provided in the home setting are generally less costly than those provided in the inpatient setting; and 2) hospice care focuses on proactive symptom management that is less medically aggressive than conventional curative treatments. Hospice care involves less rigorous use of expensive and often debilitating and painful ancillary services which all add to quality of life.⁸

"Sometimes we can offer a cure, sometimes only a salve, sometimes not even that. But whatever we can offer, our interventions, and the risks and sacrifices they entail, are justified only if they serve the larger aims of a person's life. When we forget that, the suffering we inflict can be barbaric. When we remember it the good we do can be breathtaking."

— **Atul Gawande**, [Being Mortal: Medicine and What Matters in the End](#)

Qualitative and quantitative research, as well as numerous patient experiences, demonstrate the benefits of the hospice program to enrollees and their family members, as well as its cost-effectiveness to Medicare, its primary payer.

In 1979, the Robert Wood Johnson Foundation and the John A. Hartford Foundation, together with the Health Care Financing Administration (HCFA)⁹ – now the Centers for Medicare & Medicaid Services (CMS) funded a demonstration project, the National Hospice Study, to "compare patients served in hospital-based and home-based hospices with terminal cancer patients receiving care from a variety of conventional (nonhospice) oncological-care settings."¹⁰ The intent of the demonstration was to determine which care models best incorporate the hospice concept.

The National Hospice Study (NHS) aimed to determine the cost-effectiveness of providing hospice care to terminally ill Medicare and Medicaid beneficiaries. Brown University was selected to evaluate the program under the direction of Vincent Mor, Ph.D. The evaluation

⁶ As exemplified by the launch of Accountable Care Organizations in 2011, the implementation of the Bundled Payments for Care Improvement (BPCI) initiative in 2013, as well as the passage of the Affordable Care Act (ACA) in 2014.

⁷ Banach, Edo. Coordinated Care Is More Than a Buzzword for Hospice Providers. National Hospice and Palliative Care Organization (NHPCO). April 24, 2018. <https://www.nhpco.org/press-room/press-releases/op-ed-coordinated-care>

⁸ Mor, V., Greer, DS., and Kastenbaum, R. The Hospice Experiment. 1988. The Johns Hopkins University Press.

⁹ HCFA was the name for CMS beginning in 1977.

¹⁰ Mor, V., Greer, DS., and Kastenbaum, R. The Hospice Experiment. 1988. The Johns Hopkins University Press

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found that hospice (both home-based programs and hospital-based programs) was less costly than conventional care over the last year of life. “Despite the high costs associated with the entry of patients into hospice relatively early in the course of the terminal phase of their disease, the size of the cost differences in the last month or two before death more than make up for the extra costs of extended stay in hospice.”¹¹ Demonstration findings also showed declining intensity in ancillary services and number of inpatient days provided to hospice patients as compared to non-hospice patients.¹²

As the National Hospice Study was being completed, advocates for the inclusion of hospice in the Medicare program began working tirelessly with members of Congress and mobilized a large grass roots force. Legislation to create a Medicare Hospice Benefit had been introduced in December of 1981 in the House (H.R. 5180, sponsored by Reps. Leon Panetta, D-CA, and Bill Gradison, R-OH) and in the Senate (S. 1958, by Sen. Bob Dole, D-KS). Their bill enjoyed favorable hearings in the House Ways and Means Health Subcommittee in March of 1982, but budget issues blocked its way forward. Looking for a legislative vehicle, bill sponsors and advocates determined that the budget bill being debated in the Senate was an option. On July 22, 1982, during a debate in the U.S. Senate chambers over technical provisions of the Tax Equity and Fiscal Responsibility Act, Senator John Heinz (D-PA) walked around the Senate chamber getting signature supporting an amendment to establish hospice under Medicare. He needed, and got, the needed 68 signatures to overcome an anticipated objection to the amendment. The amendment passed and a hospice benefit under Medicare was created.¹³ HCFA subsequently issued regulations issued by HCFA (now CMS) in December 1983.

The Medicare Care Choices Model (MCCM) is designed to learn whether the value hospice brings to the patient and family, during a time when the patient is eligible to elect hospice, as determined by the attending physician and hospice medical director, sheds light on the rate of patients choosing hospice or not. The MCCM provides a new option for Medicare beneficiaries to receive palliative care services from certain hospice providers without waiving their right for coverage from all parts of the Medicare program. CMS will evaluate whether concurrent care prior to the selection of the Medicare hospice benefit can improve the quality of life and care received by Medicare beneficiaries and increase patient satisfaction.¹⁴ Participating hospices were randomly assigned to one of two cohorts. The first hospice cohort began providing services to beneficiaries on January 1, 2016, and the second cohort began providing services on January

¹¹ Mor V, Kidder D. (1985) Cost savings in hospice: Final results of the National Hospice Study. *Health Services Research*, Vol 20, No.4: 407-422.

¹² Mor V, Greer, DS., and Kastenbaum, R. *The Hospice Experiment*. The Johns Hopkins University Press Baltimore and London. 1988.

¹³ TEFRA 1982, § 122, Pub. L. 97-248

¹⁴ <https://innovation.cms.gov/initiatives/medicare-care-choices/>

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1, 2018. CMS originally planned to select at least 30 Medicare-certified hospices to participate in the Model. However, due to robust interest, CMS invited over 140 Medicare-certified hospices to participate in the Model and increased the duration of the Model to 5 years.

Background: The History of Hospice

The first hospice – St. Christopher’s Hospice – was founded by Dame Cicely Saunders in 1967 in London, England.¹⁵ Recognized as the founder of the hospice movement, Dame Cicely was trained as a physician, nurse, and social worker, with a vision to transform end-of-life care where pain and symptom control would be linked with compassionate care, teaching, and clinical research. Having volunteered at a hospital early in life and witnessing the aftercare of patients with terminal illness, Dame Cicely internalized what she saw and came to believe that people should die with dignity, compassion, and respect.

“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, nurse, physician, social worker, writer, and founder of hospice movement (1918 – 2005).

Furthermore, she also introduced the idea that not being able to cure a patient was not a sign of failure.¹⁶ For these reasons, she pioneered research on the use of morphine for pain and symptom control, and the efficacy of home care teams appropriate for end-of-life care. She also developed bereavement service programs at St. Christopher’s Hospice to help families beyond the death of the patient.¹⁷ Dame Saunders’ original insights continue to be the founding principles of hospice care today.

Defining Hospice Care

Hospice is grounded in the philosophical approach of providing person-centered care of body and mind to terminally ill patients and their families. Eligibility for hospice includes eligibility for Medicare Part A and a prognosis of six months or less if the disease runs its normal course. A patient elects the hospice benefit based on an informed decision to waive the right to other Medicare benefits. Hospice does not attempt to prolong life, but instead strives to improve the quality of life for the time the patient has left.

Hospice care is delivered by an interdisciplinary care team which includes a physician, nurse, social worker, and counselor as core disciplines. Other disciplines may also be involved in providing care to the patient and family, including hospice aides, chaplains, therapists –

¹⁵ Dame Cicely Saunders. St. Christopher’s. <http://www.stchristophers.org.uk/about/damecicelysaunders>

¹⁶ Dame Cicely Saunders. The BMJ. <https://www.bmj.com/content/suppl/2005/07/18/331.7509.DC1>

¹⁷ Dame Cicely Saunders. StChristopher’s. <http://www.stchristophers.org.uk/about/damecicelysaunders>

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including physical therapists, occupational therapists, speech-language pathologists, art, music and massage therapists. The services are developed as a part of the hospice's plan of care, together with the individual patient and their family and are adjusted as the patient's illness progresses.

Community-based palliative care provides pain and symptom management as well as psychological and emotional support for those patients with advanced illness. If the palliative care team believes that curative or aggressive treatment is no longer meeting the patient's goals of care, the physician or non-physician practitioner leading the care team may recommend a transition to hospice care¹⁸. Although the curative treatments for the terminal illness provided under palliative care cease when a patient enters hospice, some care that was considered curative may be adapted or adjusted to be palliative in nature. The hospice will help the patient and family adjust to the "new" modalities and realities of care and to make the transition to hospice seamless. Pain and symptom management and other comfort care services continue until the patient dies.

As of 2017, nearly 4,500 hospices were participating in the Medicare program in all 50 states. The Medicare Payment Advisory Commission (MedPAC) reported hospice services in 2017 totaled \$17.9 billion in Medicare expenditures.¹⁹ In 2017, 1.5 million Medicare beneficiaries received hospice services and 16.7 percent of those beneficiaries were discharged alive. The patient may leave hospice care at any time by "revoking" their hospice benefits and returning to regular fee-for-service Medicare. The hospice may discharge the patient alive for prolonged prognosis, moving out of the hospice's service area or for cause.²⁰

The Social Security Act contains a detailed definition of hospice care at Section 1861(dd). "Hospice care" refers to when any of the following services or items are provided to a terminally ill individual by a hospice program.²¹

¹⁸ National Institute on Aging. What are Palliative Care and Hospice Care? 2017. <https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care>

¹⁹ *Assessing Payment Adequacy and Updating Payments: Hospice Services*. MedPAC presentation to MedPAC commissioners dated December 7, 2018.

²⁰ Medicare Program; FY 2019 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements. The Federal Register May 8, 2018.

²¹ Compilation of The Social Security Laws. Part E – Miscellaneous Provisions. Social Security Administration. https://www.ssa.gov/OP_Home/ssact/title18/1861.htm

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Hospice Services:

- Nursing care provided by or under the supervision of a registered professional nurse,
- Physical or occupational therapy, or speech-language pathology services,
- Medical social services under the direction of a physician,
- Services of a trained hospice aide approved by the Secretary and homemaker services,
- Medical supplies (including drugs and biologicals) and the use of medical appliances, while under such a plan,
- Physicians' services,
- Short-term inpatient care (including both respite care and procedures necessary for pain control and acute and chronic symptom management) in an inpatient facility meeting such conditions as the Secretary determines to be appropriate to provide such care, but such respite care may be provided only on an intermittent, nonroutine, and occasional basis and may not be provided consecutively over longer than five days,
- Counseling (including dietary counseling) with respect to care of the terminally ill individual and adjustment to his death, and
- Any other item or service which is specified in the plan and for which payment may otherwise be made under this title.

Source: The Social Security Act Section 1861(dd)(1)

Purpose and Context

Hospice Care is Characterized by its Patient and Family-Centered, Holistic Approach

Findings from research studies with terminally ill patients indicate seven core domains of end-of-life needs. These are (1) time, (2) social, (3) physiological, (4) death and dying, (5) safety, (6) spirituality, (7) change & adaptation. The prevalence, rather than just the occurrence, of patients' reported needs provides further insight into their relative importance.²² Effective communication is therefore a primary ingredient for understanding and assessing patients' needs as a means of providing optimal hospice care.

Hospice care focuses on promoting comfort rather than prolonging life for patients with terminal illnesses, which are illnesses with little or no chance of recovery and that will most likely result in death in the near future.^{23, 24} Hospice care employs a patient and family-centered, holistic approach, with the goal of providing the best possible quality of care at the end of life.

This goal is achieved through an interdisciplinary care team (see Exhibit 1 containing the interdisciplinary care team model)—consisting of physicians specializing in hospice and palliative medicine, nurses with education in caring for dying patients, social workers, therapists, chaplains and other spiritual leaders, hospice aides and specially trained volunteers. The integrated team provides pain and symptom management to the patient and supports the family members both before and after the patient's death.

Not only will the patient benefit from family involvement during their time in hospice care where family caregivers may provide support, comfort, and help with the patient's daily activities, but family members can be supported during the grief and bereavement process.

Exhibit 1: Hospice Interdisciplinary Care Team Model



²² von Gunten C, Ferris F, Emanuel L: Ensuring Competency in End-of-Life Care. *JAMA* 2000, 284:3051-3057.

²³ Torpy et al. Hospice Care. *JAMA*. 2012; 308 (2): 200. Doi:10.1001/jama.2012.621. <https://jamanetwork.com/journals/jama/fullarticle/1216479>

²⁴ Pace et al. Hospice Care. *JAMA*. 2006; 295(6): 712. Doi:10.1001/jama.295.6.712. <https://jamanetwork.com/journals/jama/fullarticle/202341>

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Although hospice care does not aim for cure of the terminal illness, it may treat potentially curable conditions such as pneumonia. Finally, while most hospice patients are older, this type of care can be helpful for persons of any age suffering from any terminal illness.

The Location of Hospice Care

The most common setting for hospice care is the patient's own home or wherever the patient calls home, where more than 98 percent of days of care are currently provided.²⁵ This can include an assisted living facility, nursing home, residential hospice facility, or any other living arrangement. For hospice patients whose care needs are complex, or whose symptoms cannot be managed in any other setting, short term inpatient care can be provided in a hospice inpatient facility, hospital, or skilled nursing facility. For patients receiving hospice services at home, family caregivers (and friends) are trained to provide basic care. They can administer medication, help the patient transfer from bed to chair, and help the patient eat, drink, and bathe. When hospice staff are present in the home, they assess physical and psychosocial symptoms, provide personal care services, provide spiritual support, provide guidance to family members, and discuss concerns with patients and their families.²⁶

²⁵ Medicare Program; FY 2019 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements. The Federal Register May 8, 2018.

²⁶ Where can patients receive hospice care? American Hospice Foundation. 2014. <https://americanhospice.org/learning-about-hospice/what-are-the-different-locations-where-patients-can-receive-hospice-care/>

Medicare Hospice Patient Population Characteristics

Hospice use among Medicare beneficiaries has grown rapidly since its inception. This trend varies by beneficiary characteristics, such as enrollment in traditional Medicare fee-for-service (FFS) or Medicare Advantage (MA); Medicare-only beneficiaries or beneficiaries dually eligible for Medicare and Medicaid; urban or rural residence; and age, gender, and race.²⁷

Characteristics by Medicare Eligibility Category, Age Group, and Urban vs Rural by Decedent

Table 1 shows the characteristics of Medicare beneficiaries using the hospice benefit. Hospice use is generally higher among decedents in MA than in FFS (51.9 percent vs 48.7 percent, respectively). Hospice use by decedent also varies for Medicare only and dually eligible Medicare and Medicaid decedents (51.4 percent and 44.1 percent, respectively). Not surprisingly, the rate of hospice use increases with age, with the highest prevalence among decedents age 85 and older (59.1 percent).

²⁷ Medicare Payment Advisory Commission (MedPAC). Report to the Congress: Medicare Payment Policy. Chapter 12: Assessing payment adequacy and updating payments. March 2018.

Medicare Hospice Patient Population Characteristics

This finding is in contrast to the 30 percent of Medicare decedents under age 65. In addition, hospice use is higher for urban than rural Medicare decedents ranging from 50.7 percent in urban areas to 33.8 percent in frontier areas (Table 1).²⁸

Table 1: Percent Hospice Use by Characteristics of Medicare Decedents (2016)

Decedent Characteristics	2016 (%)	Decedent Age	2016 (%)	Decedent Location	2016 (%)
MA beneficiaries	51.9%	<65	30.1%	Urban	50.7%
FFS beneficiaries	48.7%	65-74	41.4%	Micropolitan	46.3%
Medicare only	51.4%	75-84	50.7%	Rural, adjacent	45.7%
Dual eligibles	44.1%	85+	59.1%	Rural, non-adjacent	40.2%
				Frontier	33.8%

Source: Medicare Payment Advisory Commission (MedPAC) Report to the Congress: Medicare Payment Policy. Chapter 12: Assessing payment adequacy and updating payments. March 2018

Characteristics by Disease Diagnosis

Differences in Medicare beneficiary use of hospice care are also evident by principal diagnosis. Figure 2 shows the top hospice diagnoses among Medicare beneficiaries in 2016. As noted in Figure 2, Medicare beneficiaries with any diagnosis are eligible for and receive hospice care. In 2016, twenty seven percent of Medicare beneficiaries entered hospice with a primary diagnosis of cancer, higher than any other disease category.²⁹ As patients with other terminal diagnoses experience the value of hospice, the relative proportion of hospice cancer patients has decreased over time.³⁰

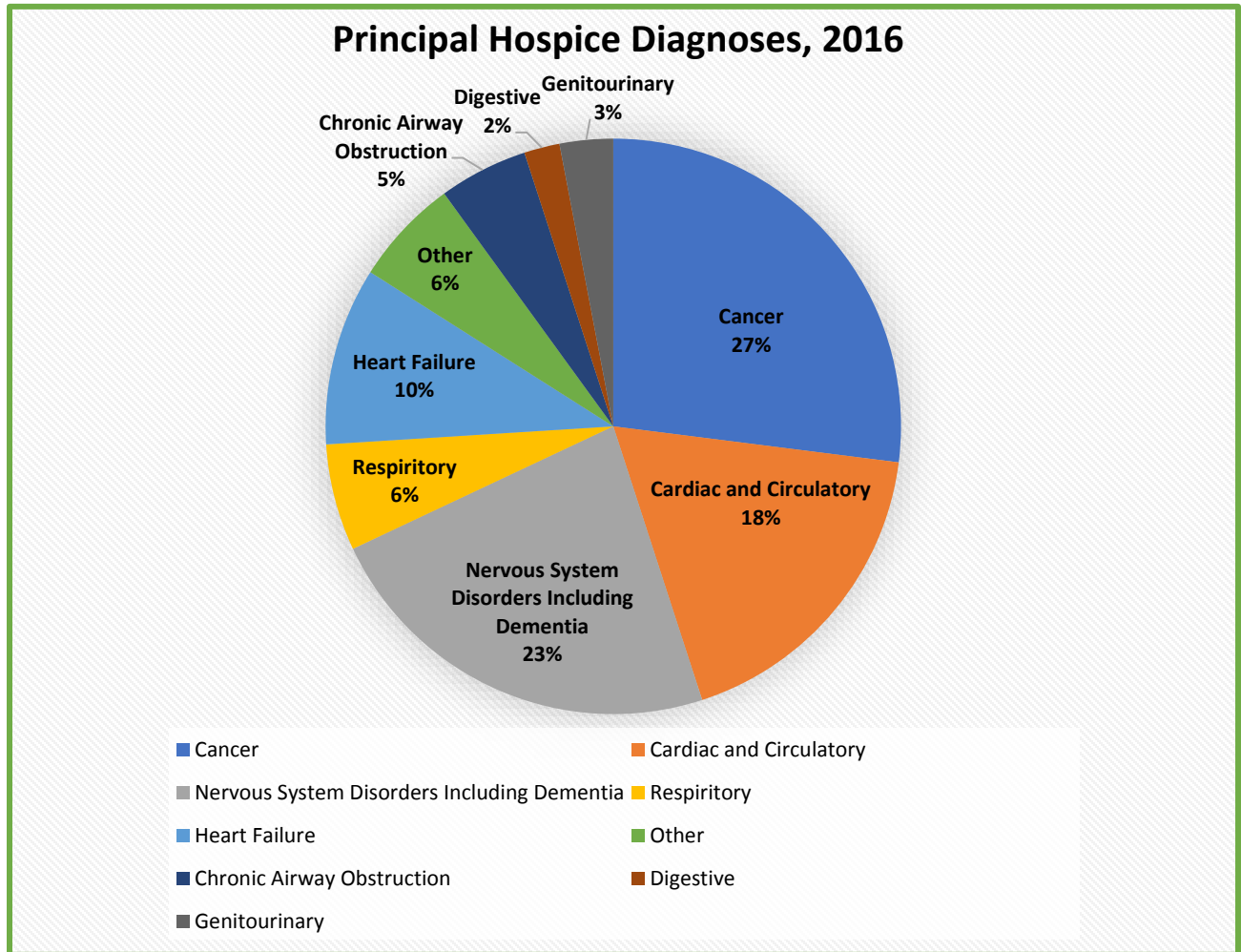
²⁸ Medicare Payment Advisory Commission (MedPAC) Report to the Congress: Medicare Payment Policy. Chapter 12: Assessing payment adequacy and updating payments. March 2018.

²⁹ A Data Book: Health Care Spending and the Medicare Program. MedPAC, June 2018.

³⁰ Aldridge, M.D., Canavan, M., Cherlin, E., Bradley, E. Has Hospice Use Changed? 2000-2010 Utilization Patterns. *Med Care.* (January 2015). 53(1): 95–101. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4262565/pdf/nihms-630205.pdf>

Medicare Hospice Patient Population Characteristics

Figure 2: Hospice User Principal Diagnoses, 2016



Source: A Data Book: Health Care Spending and the Medicare Program. MedPAC, June 2018.

Hospice Payment

Hospice Payment Model

The Medicare program pays an all-inclusive per diem payment to hospice providers. In addition to covering the cost of hospice staff visits, this payment is also intended to cover the costs of ancillary services a hospice incurs for management of the terminal illness and related conditions, such as on-call services, care planning, drugs, medical equipment, supplies, and patient transportation between sites of care that are specified in the plan of care³¹.

After holding the hospice payment structure constant from 1983 to 2016, the Medicare FY 2019 payment structure was designed and implemented to better align with the costs of providing hospice care throughout an episode, where more services are provided at the beginning and end of an episode and fewer in between (see Figure 3). Medicare beneficiaries have limited cost sharing for hospice services. For instance, only prescription drugs and inpatient respite care are potentially subject to a small copay for cost sharing. Hospices must also report either itemized charges for drugs and some Durable Medical Equipment or a total charge on the claim form each month for each patient.

As distinguished by the location and intensity of the services provided, there are four different levels of care, each with its own payment schedule as seen in Figure 3:³²

³¹ Medicare Program; FY 2019 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements. Final Rule. August 2018.

³² CMS Transmittal CR10631 with FY 2019 Hospice Rates, retrieved on November 26, 2018 at <https://www.cms.gov/Regulations-and-Guidance/Guidance/Transmittals/2018Downloads/R4086CP.pdf>

Hospice Payment

Figure 3: The Four Levels of Hospice Care with Medicare FY 2019 national rates

Note: Rates are geographically adjusted.

<p>Routine Home Care</p> <ul style="list-style-type: none"> ○ The most common level of hospice care—98 percent of all hospice days ○ Payment Schedule: <ul style="list-style-type: none"> • Days 1-60 \$196 per day • Days 61+ \$154 per day 	<p>Continuous Home Care</p> <ul style="list-style-type: none"> ○ Intended for the management of a short-term crisis in the home that involves eight or more hours of care per day, primarily nursing care ○ Payment Schedule: <ul style="list-style-type: none"> • \$41.56 per hour
<p>Inpatient Respite Care</p> <ul style="list-style-type: none"> ○ Care provided in a facility setting intended to give an informal caregiver a break ○ Payment Schedule: <ul style="list-style-type: none"> • \$176 per day 	<p>General Inpatient Care</p> <ul style="list-style-type: none"> ○ Provided in a hospital or hospice independent facility on a short-term basis to manage symptoms that cannot be managed in another setting ○ Payment Schedule: <ul style="list-style-type: none"> • \$758 per day

Hospice Payment Limits

The original design of the Medicare hospice benefit places limits on spending so that the overall costs associated with Medicare hospice care are not more than the costs of conventional care for patients at the end of life. For example, the aggregate cap on Medicare payments for an individual hospice may not exceed the total number of Medicare beneficiaries served by the hospice multiplied by the cap amount (about \$29,205 for the 2019 cap year). If the annual calculation is more than the cap amount, the hospice must repay the excess to the Medicare program.³³

³³ Medicare Program; FY 2019 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements. Final Rule. August 2018. <https://www.federalregister.gov/documents/2018/08/06/2018-16539/medicare-program-fy-2019-hospice-wage-index-and-payment-rate-update-and-hospice-quality-reporting>

Evidence of the Hospice Value Proposition

In an increasingly value based marketplace, it is important to define “value.” Many researchers agree that value in any industry should be centered on the customer; in the health care industry, this means the patient. More specifically, value in health care is often defined as quality relative to cost.^{34, 35} Since health care delivery involves multiple health care professionals and providers, value in health care is largely about coordinating care and reducing cost across all care providers without compromising outcomes. Hospice is an early example of how interdisciplinary care and coordination of services can produce value-based care. In this sense, hospice has demonstrated its value since its inception in the U.S. Evidence of its value is threefold: 1) savings to the Medicare program (the primary payer of hospice care in the US), 2) benefits to hospice patients and bereaved family members, and 3) consumer and family satisfaction.

Quantifiable Savings to the Medicare Program

Considerable evidence supports the benefits of both inpatient and outpatient palliative care under programs such as the Medicare Hospice Benefit, which is generally available to individuals aged 65 years and older in the U.S. The following presents a summary of several research studies showing the positive clinical impacts of hospice, which can translate into direct savings to the Medicare program. Our literature review indicates that, depending on the length of stay and characteristics of the patient population, the Medicare hospice benefit can generate savings anywhere from \$2,309 per hospice user³⁶ to \$17,903 per hospice user.³⁷

³⁴ Wegner, SE. Measuring Value in Health Care. *North Carolina Medical Journal*. July-August 2016. 77(4):276-278. <http://www.ncmedicaljournal.com/content/77/4/276.full>

³⁵ Porter, ME. What Is Value in Health Care? *N Engl J Med* 2010; 363:2477-2481. DOI:10.1056/NEJMp1011024. <https://www.nejm.org/doi/full/10.1056/nejmp1011024>

³⁶ Taylor Jr. et al. What length of hospice use maximizes reduction in medical expenditures near death in the US Medicare program? June 2007. *Social Science & Medicine* 65 (2007): 1466-1478.

³⁷ Obermeyer et al. Association Between the Medicare Hospice Benefit and Health Care Utilization and Costs for Patients with Poor-Prognosis Cancer. *JAMA*. 2014; 312(18):1888-1896.

Evidence of the Hospice Value Proposition

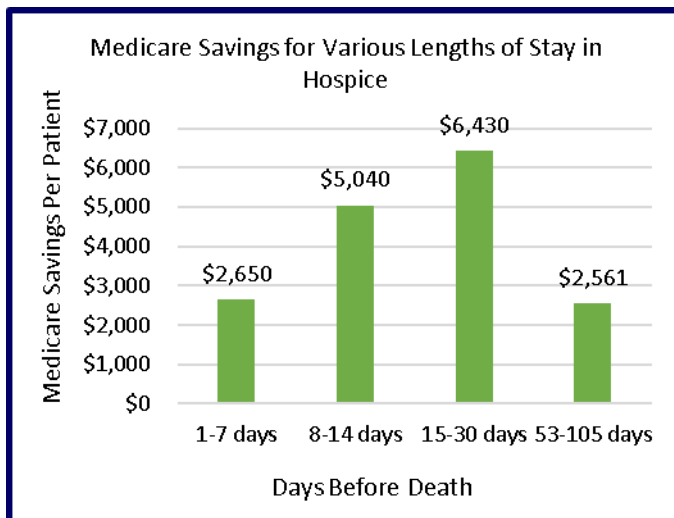
What length of hospice use maximizes reduction in medical expenditures near death in the US Medicare program?

An early study by Taylor and colleagues had found that that hospice reduced Medicare program expenditures during the last year of life by an average of \$2,309 per hospice user, increasing to \$3,500 per user at a length of stay between 53 and 108 days.³⁸ More recently, in a study using Health and Retirement Study data linked to Medicare claims, Kelley and colleagues found Medicare savings among this group, but also found savings among those enrolled for 1 to 7 days before death and also 8 to 14 days and 15 to 30 days. Savings were primarily from reductions in the use of hospital and intensive care services at the end of life.³⁹ These results support the earlier results from the Taylor study.

Study Population:

- Hospice Users: n = 1,064
- Non-hospice controls: n = 2,005

Findings: In a sample matched for individual health, functional, and social characteristics, Medicare costs for patients enrolled in hospice were significantly lower than those of non-hospice enrollees across all study periods ($p < .01$). The authors concluded that instead of attempting to limit Medicare hospice participation, the Centers for Medicare and Medicaid Services should focus on ensuring the timely enrollment of patients who desire the benefit.



Source: Kelley et al, 2013

³⁸ Taylor Jr. et al. What length of hospice use maximizes reduction in medical expenditures near death in the US Medicare program? June 2007. *Social Science & Medicine* 65 (2007): 1466-1478.

³⁹ Kelley AS, Deb P, Qingling D, et al. (2013) Hospice enrollment saves money for Medicare and improves care quality across a number of different lengths of stay. *Health Affairs*, Vol 32, No 3:552-561.

Evidence of the Hospice Value Proposition

Association between the Medicare Hospice Benefit and Health Care Utilization and Costs for Patients with Poor Prognosis Cancer.

In this sample of Medicare fee-for-service beneficiaries with poor-prognosis cancer, those receiving hospice care vs not (comparison group) had significantly lower rates of hospitalization, intensive care unit admission, and invasive procedures along with significantly lower total costs during the last year of life.⁴⁰

Study Population:

- Hospice Users: n = 18,165
- Non-hospice controls: n = 18,165

Findings: In a nationally representative 20 percent sample of fee-for-service Medicare beneficiaries who died in 2011, the authors used a two-stage matching approach to create pairs of beneficiaries with poor prognosis cancers (e.g., brain, pancreatic, metastatic malignancies) who were as similar as possible, but had made different choices concerning hospice enrollment at the same point in time before death.

The primary outcome was health care utilization in the last year of life, the secondary outcome was total costs. Non-hospice beneficiaries had more hospitalizations, and higher rates of intensive care admission and invasive procedures. Overall costs during the last year of life were \$71,517 for non-hospice vs \$62,819 for hospice users, a statistically significant difference of \$8,697. Furthermore, a significantly lower percentage of hospice users died in the hospital or SNF (14 percent vs. 74.1 percent for non-hospice beneficiaries).

Care Utilization in the Last Year of Life		
	Non-hospice, % (95% CI)	Hospice, % (95% CI)
Hospital admission	65.1 (64.4-65.8)	42.3 (41.5-43.0)
ICU Admission	35.8 (35.1-36.5)	14.8 (14.3-15.3)
Invasive Procedures	51.0 (50.3-51.7)	26.7 (26.1-27.4)
Death in hospital or SNF	74.1 (73.5-74.8)	14.0 (13.5-14.5)
Long term hospital/SNF	23.9 (23.3-24.5)	10.5 (10.1-11.0)
Total Costs (\$)	71,517 (70,543-72,490)	62,819 (62,082-63,557)

Source: Obermeyer, et al (2014).

⁴⁰ Ober Obermeyer et al. Association Between the Medicare Hospice Benefit and Health Care Utilization and Costs for Patients with Poor-Prognosis Cancer. *JAMA*. 2014; 312(18):1888-1896.

Evidence of the Hospice Value Proposition

Cost Savings and Enhanced Hospice Enrollment with a Home-Based Palliative Care Program Implemented as a Hospice-Private Payer Partnership.

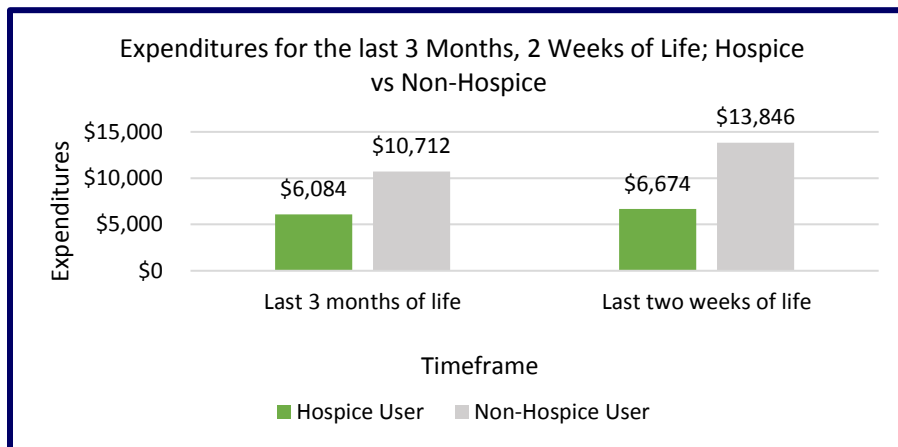
The aim of the study was to evaluate the clinical impact of a home-based palliative care program, Home Connections, implemented as a partnership between a not-for-profit hospice and two private insurers. Measured outcomes included 1) advance directive completion, 2) site of death, 3) symptom severity over time, 4) program satisfaction, 5) hospice referral and 6) average length of stay.

The Center for Hospice & Palliative Care (Cheektowaga, New York) established Home Connections (HC), a home-based palliative care program, in 2008. HC serves Erie County, New York, and is available to adult patients, 18 years or older, with advanced chronic illness. HC serves patients upstream from the Medicare Hospice Benefit, so patients may still be receiving aggressive or cure-focused treatments and do not necessarily have an expected prognosis of six months or less.

Study Population:

- Included in Analyses: n = 499
- Hospice enrolled: n = 147

Findings: A prospective, observational study of a single cohort of commercially insured patients by Kerr et al. (2014) found that an overall savings of \$4,628 (\$10,712 - \$6,084) was associated with hospice enrollment per user per month for the last 3 months of life. The amount of savings was almost doubled to \$7,172 (\$13,846 - \$6,674) when researchers looked at only the last two weeks of life for these patients.⁴¹



⁴¹ Kerr et al. Cost Savings and Enhanced Hospice Enrollment with a Home-Based Palliative Care Program Implemented as a Hospice-Private Payer Partnership. *J Palliative Med*, 2014; 17(12).

Evidence of the Hospice Value Proposition

What length of hospice use maximizes reduction in medical expenditures near death in the US Medicare program?

The Duke cost study, a seminal retrospective case/control study of Medicare beneficiaries by Taylor Jr. and colleagues⁴² found that hospice use reduced Medicare program expenditures during the last year of life by an average of \$2,309 per hospice user:

Study Population:

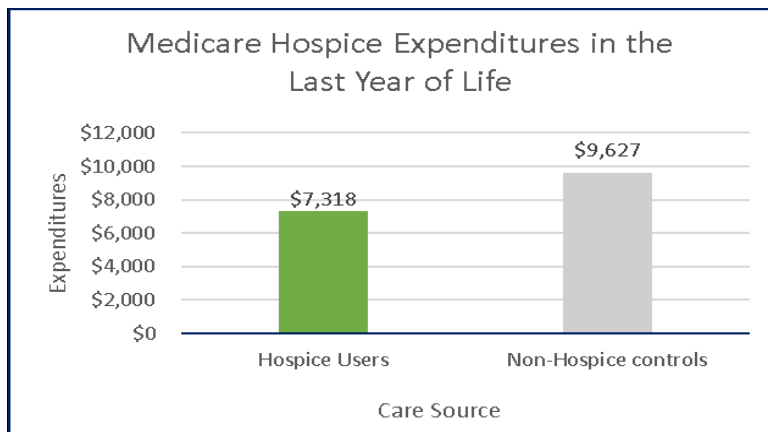
- Hospice Users: n = 1,819
- Non-hospice controls: n = 3,638

Finding: Savings are most pronounced during the user's last 72 days of life;

- starting with \$10 on the 72nd day
- increasing to \$750 on the day of death

When differentiating the study population by primary condition for hospice admission and examining a length of stay between the last 58-103 days of life this average saving increased to:

- around \$3,500 per user for primary conditions other than cancer; and
- a maximum reduction of about \$7,000 in Medicare expenditures per user with a primary diagnosis of cancer.



⁴² Taylor Jr. et al. What length of hospice use maximizes reduction in medical expenditures near death in the US Medicare program? June 2007. *Social Science & Medicine* 65 (2007): 1466-1478.

Evidence of the Hospice Value Proposition

Cost Savings Associated with Expanded Hospice Use in Medicare.

This study examined hospice savings to Medicare by simulating various uptake percentages of hospice care by decedent Medicare beneficiaries with terminal cancer and by the duration of hospice stay. Based on a regression model estimating difference in weekly costs between matched hospice and nonhospice beneficiaries, as a function of age, sex, HRR, comorbidity, and time from diagnosis to death. Using coefficients from this model, the authors estimated costs for all beneficiaries with poor-prognosis cancers at the beneficiary-week level, under hypothetical scenarios of increased hospice uptake. Specifically, the authors varied the percentage of beneficiaries enrolled in hospice (assigning a random sample of $f = 20$ percent, 40 percent, ... 100 percent of all beneficiaries to hospice) and length of hospice stay (setting length to $w = 2, 4, 8, \dots 24$ weeks for all those assigned to hospice).

Findings: Estimated annual cost savings ranged from \$316 million if 20 percent of the decedent beneficiaries used hospice care for a duration of 4 weeks to \$2.43 billion if 100 percent of the decedent beneficiaries used hospice care for a duration of 24 weeks. The study was based on the estimate that about 60 percent of decedent Medicare beneficiaries enter hospice care for an average stay of under two weeks, the hospice program could save the Medicare program \$705 million annually. In addition, since the general consensus is that the most reasonable length of stay is three months, and at the estimate of 60 percent hospice uptake, an annual savings of \$1.34 billion could be achieved.

Annual Cost Savings by Hospice Uptake and Duration of Hospice Stay (\$ MILLIONS)							
Hospice Uptake Medicare Decedent (%)	Duration of Hospice Stay (weeks)						
	2	4	8	12	16	20	24
20%	\$237	\$316	\$411	\$446	\$466	\$484	\$487
40%	\$469	\$630	\$825	\$890	\$935	\$965	\$970
60%	\$705	\$940	\$1,235	\$1,340	\$1,395	\$1,445	\$1,455
80%	\$940	\$1,260	\$1,645	\$1,785	\$1,860	\$1,925	\$1,940
100%	\$1,175	\$1,570	\$2,060	\$2,230	\$2,330	\$2,410	\$2,430

Source: Powers et al. Cost Savings Associated with Expanded Hospice Use in Medicare. *J Palliative Med.* 2015 May 1; 18(5):400-401.⁴³

⁴³ Powers et al. Cost Savings Associated with Expanded Hospice Use in Medicare. *J Palliative Med.* 2015 May 1; 18(5):400-401.

Evidence of the Hospice Value Proposition

The value proposition of the hospice program is demonstrated by the numerous research studies showing Medicare savings associated with the program. The weight of the evidence is that appropriate use of hospice can generate savings in Medicare across all lengths of stay, and savings are more pronounced for patients with more comorbidities and longer stays in hospice.

There is growing evidence that hospice provides high-value, high-quality and effective care, that patients and families choose hospice as a benefit under Medicare because of the holistic care that is provided to patients and their families, as well as the potential for cost savings, as demonstrated by studies that span four decades of quantitative and qualitative research.

Studies as well as real life patient stories have consistently demonstrated the positive impact hospice conveys to those suffering with advanced and terminal illnesses and their primary caretakers.^{44, 45, 46, 47, 48,}

Documented Benefits to Hospice Patients and Families

Hospice provides patients the choice of managing pain and symptoms of terminal illnesses and being comfortable in the last months of life. Hospice use is not “giving up.” In a study of 1,970 propensity-score-matched individuals with advanced cancer and their family members, Kumar and colleagues examined the association between receipt of hospice and the relief of common pain and anxiety symptoms, patient-goal attainment, and quality of end-of-life care; and found that not only do families of patients enrolled in hospice more often report that patients received “just the right amount” of pain medication, they are also more likely to report that the patient’s end-of-life wishes were followed, and the patient had “excellent” quality of care during the end stage of life.⁴⁹ The authors also reported that longer hospice stays were associated with higher patient and family satisfaction and those

“Hospice is the only health care program that takes care of both the patients and their family members.”

~ **Vincent Mor, Ph.D.**, Professor of Health Services, Policy and Practice. Brown University.

⁴⁴ Kumar et al. Family Perspectives on Hospice Care Experiences of Patients with Cancer. *Journal of Clinical Oncology*. February 1, 2017. 35(4): 432-439. DOI:10.1200/JCO.2016.68.9257.

⁴⁵ Teno JM et al. Timing of referral to hospice and quality of care: length of stay and bereaved family members' perceptions of the timing of hospice referral. *J Pain Symptom Manage*. 2007 Aug; 34(2): 120-5. Epub 2007 Jun 21. <https://www.ncbi.nlm.nih.gov/pubmed/17583469>

⁴⁶ Gazelle, Gail. Understanding Hospice – An Underutilized Option for Life’s Final Chapter. *N Engl J Med* 2007; 357(4): 321-324.

⁴⁷ Hospice Stories. Pathways. 2018. <https://www.pathwayshealth.org/hospice-stories/>

⁴⁸ Supporting Patients with Special Needs. CareDimensions.2018. <https://www.caredimensions.org/about-us/newsroom/patient-stories.cfm?story=18&title=Supporting%20Patients%20with%20Special%20Needs>

⁴⁹ Kumar et al. Family Perspectives on Hospice Care Experiences of Patients with Cancer. *Journal of Clinical Oncology*. February 1, 2017. 35(4): 432-439. DOI:10.1200/JCO.2016.68.9257.

Evidence of the Hospice Value Proposition

who receive hospice care are more likely to die in their preferred place.⁵⁰ Similarly, in a collaborative study between the NHPCO and the Brown University Medical School, researchers found that being referred to hospice “too late” was associated with more unmet needs, higher reported concerns, and lower satisfaction.⁵¹

Site of death has been suggested as a quality measure for end-of-life care. Population surveys indicate a majority of respondents (including those with a serious or terminal illness) report wanting to die at home, in actuality most still die in an institutional setting.⁵²

Patient Experiences

To put the many statistics presented earlier in this report into perspective, the *New England Journal of Medicine* provided case studies of the benefits of hospice from a patient’s view.⁵³

Mr. G

Mr. G is an 83 years old patient admitted to hospice due to class IV heart failure, end-stage coronary artery disease, and insulin-dependent diabetes. Relieved that hospice does not actually mean imminent death, Mr. G started his hospice care because he did not want to be re-hospitalized. Not only did the interdisciplinary team manage his pain and anxiety, they also attended to his and his wife’s non-medical needs. Mr. G was helped to dress and take care of personal hygiene an hour each day for 5 days a week and had a social worker who assisted with grocery shopping and provided companionship. Because Mr. G thought his illness was a sign of divine punishment, the social worker brought on a hospice chaplain to the care team, all the while attending to family member’s fear about the future.

Emma

Emma received her breast cancer diagnosis just days after her honeymoon with husband Jim. Two years later, when Emma’s disease progressed, she was referred to her hospice team of nurse, social worker, and hospice aide. To honor Emma’s request, the social work taught her breathing and guided meditation techniques designed specifically for cancer patients, allowing Emma to be an active participant in her own care. When her condition further deteriorated, the hospice team gently informed Emma’s family members. At the end, Emma was able to pass away peacefully at her own home, with her support system – husband, sister, father, and mother-in-law – by her bedside. Jim later wrote “the hospice staff was terrific. They helped ease her pain with their care and treatment. I really appreciated their assistance in doing so.”

⁵⁰ Ibid.

⁵¹ Teno JM et al. Timing of referral to hospice and quality of care: length of stay and bereaved family members’ perceptions of the timing of hospice referral. *J Pain Symptom Manage*. 2007 Aug; 34(2): 120-5. Epub 2007 Jun 21. <https://www.ncbi.nlm.nih.gov/pubmed/17583469>

⁵² Teno J M, Gozalo PL, Bynum J p w, et al. Change in end-of-life care for Medicare beneficiaries: Site of death, place of care, and healthcare transitions in 2000, 2005, and 2009. *JAMA*. February 6, 2013. Vol 309, No.5: 470-477.

⁵³ Porter, ME. What Is Value in Health Care? *N Engl J Med* 2010; 363:2477-2481. DOI:10.1056/NEJMp1011024. <https://www.neim.org/doi/full/10.1056/nejmp1011024>

Evidence of the Hospice Value Proposition

These personal experiences, regardless of the age of the patient, location of their care or principal diagnosis for hospice admission, are examples of testimonies to the patient's perceived value of this interdisciplinary approach to coordinated care, which includes both the patient and their family. Hospice fulfills patients' specific yet diverse needs, often expanded beyond what traditional curative treatment can do.

Family Members' Experiences

In addition to the psychosocial benefits to the patient, benefits of hospice are available to dying patients' family members, those who are left behind.⁵⁴ Studies have consistently demonstrated the importance of hospice care to bereaved family members. In conducting their prospective, longitudinal, multisite study of patients with advanced cancer and their caregivers, Wright et al. found that even after adjusting for caregivers' baseline mental health, mourning caregivers whose loved ones died in an intensive care unit (ICU) and hospital were more likely to develop psychiatric symptoms than their counterparts whose loved ones died at home under hospice care.⁵⁵ Bereaved caregivers of non-hospice patients also demonstrated an increased risk for post-traumatic stress disorder (PTSD), suggesting that caregivers' experiences at the ICU and hospital may be traumatic.

Studies have demonstrated the beneficial effects on outcomes when palliative care/hospice services are introduced into routine cancer care.

~ **May et al.** Palliative Care Teams' Cost-Saving Effect Is Larger for Cancer Patients with Higher Numbers of Comorbidities. *Health Affairs* 2016, 35(1): 44-53

To expand upon this effect, a prospective cohort study of 174 primary family caregivers of cancer patients who enrolled in hospice examined the association between hospice length of stay and depressive disorders in caregivers. The findings demonstrate that in comparison to caregivers whose loved ones stayed in hospice for a longer period of time, caregivers of patients enrolled in hospice for 3 or fewer days were significantly more likely to develop major depressive disorder, 24.1 percent compared to 9.0 percent for those with a longer stay in hospice. The effect remained true after adjusting for confounding factors.⁵⁶

⁵⁴ Naierman N and Johanna Turner. Debunking the Myths of Hospice. American Hospice Foundation. <https://americanhospice.org/learning-about-hospice/debunking-the-myths-of-hospice/>

⁵⁵ Wright et al. Place of Death: Correlation With Quality of Life of Patients With Cancer and Predictors of Bereaved Caregivers' Mental Health. *J Clin Oncol*. 2010 Oct 10; 28(29): 4457-4464.

⁵⁶ Bradley EH et al. Depression among surviving caregivers: does length of hospice enrollment matter? *Am J Psychiatry*. 2004 Dec; 161(12): 2257-62.

Hospice: A Service Underutilized

As noted above, although the majority of the people expressed the desire to die at home, 20 percent of Medicare patients still die in the hospital.^{57, 58} In fact, two independent studies reported that as of 2017, more than forty million Americans with serious health problems do not have access to hospice and palliative care.^{59, 60}

Despite the benefits of hospice care being widely reported, why does hospice still remain an underutilized service? The answer may lie within some of the myths and misunderstandings surrounding this program. These beliefs can include, but are by no means limited to, belief that: 1) hospice is a place, 2) hospice means giving up on life, 3) hospice hastens death, 4) hospice requires family involvement or 5) hospice is only appropriate for the last few days of life.^{61, 62} These widely held beliefs are discussed below.

⁵⁷ Teno, J.M., Gozalo, P., Trivedi, A.N., Bunker, J., Ogarek, J., Mor, V. Place of Care in Advanced Cancer: Site of Death, Place of Care, and Health Care Transitions Among US Medicare Beneficiaries, 2000-2015. *Journal of the American Medical Association*. July 17, 2018. <https://jamanetwork.com/journals/jama/article-abstract/2686318>

⁵⁸ Percent of Death Occurring in Hospital. *The Dartmouth Atlas of Health Care*. <http://www.dartmouthatlas.org/data/table.aspx?ind=15>

⁵⁹ Kelley AS. Defining "serious illness." *J Palliat Med*. 2014;17(9):985.

⁶⁰ Schoenman JA. The concentration of health care spending. National Institute for Health Care Management Research and Educational Foundation. 2012.

⁶¹ Temel et al. Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer. *N Engl J Med* 2010; 363:733-742. <https://www.nejm.org/doi/full/10.1056/NEJMoa1000678>

⁶² Connor, SR et al. Comparing Hospice and Nonhospice Patient Survival Among Patients Who Die Within a Three-Year Window. *Journal of Pain and Symptom Management* 2007; 33(3):238-246. <https://www.nhpco.org/sites/default/files/public/JPSM/march-2007-article.pdf>

Hospice: A Service Underutilized

Common Misconceptions That Lead to Underutilization of Hospice

Hospice is a place: As discussed above, hospice is not a place, but rather a concept of care that can take place anywhere the patient wishes. The place of care can range from the patient's home or anywhere the patient calls home, to an assisted living facility, to a nursing home, to another group living situation, to a hospital.

Hospice is only when there is no hope: Instead of viewing hospice as a hopeless last resort, hospice care has the capability of showing patients and their caregivers how fulfilling the end of life can be by focusing on personal, familial, and spiritual connections. In fact, many family members report looking back and cherishing their hospice experience.

Hospice hastens death: Studies have consistently suggested that patients enrolled in hospice live longer than those who did not. Connor et al studied 4,493 Medicare beneficiaries with congestive heart failure or some of the most common types of cancer for hospice admission and found that patients who received hospice services lived on average 29 days longer than those in the non-hospice comparison group. A 2010 study by Temel et al. echoed such results and reported that for patients with metastatic non-small-cell lung cancer, recipients of hospice services lived a median of 11.6 months compared to patients who did not receive hospice care (8.9 months).

Hospice requires help from family members: Contrary to the belief that hospice requires family presence, this is not a must. In fact, the hospice program recognizes that a dying patient may live alone or have family members who are unable to provide care. In those cases, hospices coordinate community resources to make such care possible.

Hospice is only for the last few days of life: Hospice is presented as an option to patients and their families when a terminally ill patient is given a prognosis of six months. A patient may choose to enter or leave hospice at any point during this time. If a patient enters hospice early on, there is greater opportunity to realize the value of hospice in managing symptoms, providing more opportunities for family time and making them more comfortable in their final days.

Hospice: A Service Underutilized

Physician Attitudes Toward Hospice

Physician readiness is often a contributing factor to underutilization of hospice. Prognostication is challenging, and survival estimates are typically inaccurate.⁶³ Oncologists and other physicians can view the death of a patient as a professional failure.⁶⁴

As a way to ease patient anxiety and to increase patient and family hope, physicians often resort to “increasing the quantity rather than quality of life”.⁶⁵ These reactions stem from the fundamental resistance to confronting death by both the physician and the patient, to which modern medical advancements have heretofore contributed. Physicians may also have the view that hospice is reserved for patients whose death is imminent, not that hospice is a well-coordinated program that focuses on helping patients to live as comfortably as possible during the end stage of life.

Death is arguably the most fearful and difficult phase of life, for both patients and their families. The hospice program, originated in England and first established in the U.S. in 1974, is a holistic approach designed to alleviate both the physical and emotional pain of the dying as well as those who are left behind. The benefits of hospice have long provided value to Medicare and other patients and families as they struggle to reconcile often conflicting emotions. Its emphasis on being patient-centered and family oriented, and on providing physical and spiritual comfort during times of stress and uncertainty are well documented.

As a well-structured and integrated program within the Medicare FFS program, numerous studies have shown favorable financial and clinical results. Yet, the program continues to be underutilized. Including the misconceptions already discussed, a patient’s own cultural beliefs, referral to hospice as an indication of physician and/or family failure, and a patient or family’s inability to recognize that the end of life is near. However, as baby boomers age, many will likely live with chronic illnesses and cancer (estimated to increase by 67 percent between 2010 and 2030),⁶⁶ making the appropriate use of hospice care more critical than ever.

The Medicare Care Choice Model (MCCM): Expanding the Hospice Concept

As with any program of care, changes in the hospice program are inevitable as the value-based health care marketplace forces providers to continually refine and improve their care

⁶³ Myers J, Selby D. Personalizing prognosis in a patient with serious illness. *CMAJ*. 2014;186(3):169-70

⁶⁴ Cancer care during the last phase of life. American Society of Clinical Oncology. *J Clin Oncol* 1998; 16:1986-96.

⁶⁵ Gazelle, Gail. Understanding Hospice – An Underutilized Option for Life’s Final Chapter. *N Engl J Med* 2007; 357(4): 321-324.

⁶⁶ Cancer increasing as baby boomers age. University of Pennsylvania School of Nursing. November 27, 2013. ScienceDaily. <https://www.sciencedaily.com/releases/2013/11/131127170055.htm>

Hospice: A Service Underutilized

offerings. CMS has recently taken the initiative to test a health care delivery and payment model. The model offers a new option for Medicare beneficiaries with advanced life-limiting illness which would provide traditional hospice services, such as comprehensive medical, psychosocial, and spiritual palliative care services from selected hospice providers, while continuing to concurrently receive services provided by other Medicare providers, including care for their terminal condition. This model is referred to as the Medicare Care Choice Model (MCCM) and began in 2014. At the time of this writing, approximately 97 hospices are participating in the Model.

The MCCM aims to evaluate whether eligible Medicare and dually eligible beneficiaries would elect to receive palliative and supportive care services typically provided by hospice if they could also continue to receive curative treatment for their terminal condition, and how this flexibility impacts quality of care and patient, family and caregiver satisfaction. Beneficiaries must be diagnosed with one of the following terminal illnesses: 1) advanced cancer, 2) chronic obstructive pulmonary disease, 3) congestive heart failure, or 4) human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS).⁶⁷ The model exposes a larger group of providers and beneficiaries to the benefits of availing themselves of the integrated, patient and family-centered program of hospice.

The MCCM is designed to: 1) increase access to supportive care services provided by hospice, 2) improve quality of life and patient/family satisfaction, and 3) inform new payment systems for the Medicare and Medicaid programs.

Due to widespread interest, CMS expanded the model from an originally anticipated 30 Medicare-certified hospices to more than 140 Medicare-certified hospices and extended the duration of the MCCM from three to five years. Participating hospice programs were randomly assigned to one of two cohorts.

The first cohort began providing services to beneficiaries on January 1, 2016, and the second cohort began providing services on January 1, 2018. Based on feedback from MCCM participants and industry stakeholders, some MCCM eligibility criteria have been changed since model initiation with the goal of facilitating wider beneficiary participation. Although initial enrollment in the demonstration was lower than expected, evaluation studies have been positive.⁶⁸ Importantly, more than four out of five MCCM enrollees (83 percent) elected the Medicare hospice benefit after an average of two months in MCCM and one month prior to death.

⁶⁷ <https://innovation.cms.gov/initiatives/medicare-care-choices/>

⁶⁸ Centers for Medicare and Medicaid Services. Medicare Care Choices Model First and Second Years Evaluation Report. <https://www.cms.gov/newsroom/fact-sheets/medicare-care-choices-model-mccm-first-two-years>

Discussion: Policy Considerations for the Future of Hospice

How Could the Medicare Hospice Benefit be Restructured in the Future?

Considerable evidence suggests that the last phase of life often involves some days, weeks, and months prior to death, which are accompanied by significant emotional distress and financial expense. For patients and their families, there are few care decisions that are more intense yet uncertain than those made near the end of life. The availability of end-of-life care that seeks to provide a unique holistic and person-centered approach is of paramount importance. Expanding the utilization of hospice requires overcoming the challenging misconceptions noted in the previous chapters as these misconceptions stem from a lack of accurate information.

Several factors make this policy brief particularly timely and relevant, not the least of which is the rapidly increasing number of older Americans with some combination of frailty, physical and cognitive disabilities, chronic illness, and functional limitations. Evidence continues to mount that goals of care discussions lead to better outcomes, particularly improved quality of life near the end of life and reduced costs. Life threatening illness, whether it can be cured or controlled, carries significant burden of suffering for patients and their families and that this suffering is and can be effectively addressed by the

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Medicare Hospice Benefit. Hospice can help ensure that the patient's final time is spent in comfort and that the family's needs are attended to both before and after the patient dies.

In this section of the paper, we discuss several ideas that are currently being put forward by both providers and policymakers concerning updating or restructuring the Medicare Hospice Benefit to better align with the systematic movement toward value-based care across the continuum.

Additionally, the hospice patient mix is changing, necessitating a re-examination of the various features of the hospice benefit, such as the 6-month prognosis eligibility requirement.⁶⁹ Since data show that increasingly more patients enter hospice due to nervous system disorders and dementia-related conditions, instead of cancer, it could be beneficial to remove this regulation thus allowing hospices to provide longer care to those patients who are in need.⁷⁰ While these conditions are generally terminal, their duration can be longer than six months and this more extended duration of terminal illness should not mean that these patients do not qualify for hospice.

A couple of model initiatives have recently been introduced by CMS (e.g., the Medicare Care Choices Model (MCCM) and the Medicare Advantage Value Based Insurance Design (VBID) Model). Ideas being tested include the provision of concurrent care, extending the prognosis requirement to 12 or 18 months, and better integrating community-based palliative care with hospice care to more broadly create a full continuum of advanced illness care. Under VBID, Medicare Advantage organizations are able to propose reduced cost-sharing and/or additional supplemental benefits, including non-primarily health related supplemental benefits, for targeted enrollees.

A full continuum of care would mean that patients and their families can access needed services as they are able to grasp the finality of an advanced or terminal illness. The MCCM allows for the patient to receive services without a requirement to elect the Medicare hospice benefit and waive other parts of Medicare. Some patients and families cannot fully accept the idea of forgoing curative care when they first receive a terminal diagnosis. Over time, as they are able to accept the situation, families are better able to recognize that interventions solely to preserve life may not be in the best interests of their family member.

⁶⁹ National Hospice and Palliative Care Organization. Facts and Figures: Hospice Care in America. 2017 Edition. https://www.nhpco.org/sites/default/files/public/Statistics_Research/2017_Facts_Figures.pdf

⁷⁰ Medicare Program; FY 2019 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements. Federal Register, May 8, 2018.

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In 2021, the Medicare Advantage VBID model will add hospice benefits to those MA plans who apply. This will allow CMS to test the inclusion of hospice in MA through a model, with opportunities for learning and adjusting the model parameters.

How can policy support better coordination of the hospice benefit with Medicare fee-for-service or Medicare Advantage?

Hospice care provides services for a terminal illness and the related conditions. Some Medicare beneficiaries utilizing hospice may experience a condition that is unrelated to the reason for their hospice stay. In these cases, beneficiaries may receive traditional Medicare or private insurance services and the hospice will typically coordinate and collaborate with other providers to ensure a seamless care continuum.

In some cases, providing primary care providers education on advance care planning and goals of care discussions could also improve timely access to hospice care for terminally ill individuals and foster better coordination of hospice with other types of care. Policies that support physicians' best judgment provide a safe harbor for those providers making difficult decisions concerning a terminal patient's prognosis and determining hospice eligibility.

CMS has begun developing a comprehensive assessment instrument for hospice care to align with other Post-Acute Care (PAC) settings, where feasible and practical.⁷¹ The Hospice Evaluation and Assessment Reporting Tool (HEART) is an instrument that must include the ability to establish goals of care consistent with goals and preferences, and values the person and caregiver in the care continuum with an emphasis on physical, psychosocial, spiritual, and emotional support. CMS is working diligently to develop the instrument after pilot testing provided feedback for developers.

⁷¹ CMS Hospice Quality Reporting Program at <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/HEART.html>, accessed March 1, 2019

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What policies can enable hospice to be more widely utilized?

Another barrier that needs to be addressed is the limited number of hospice care specialists. Only recently (in 2008) did the American Board of Medical Specialties begin to certify physicians in the practice of hospice and palliative medicine.

“Hospice is many things. Hospice is home care with inpatient back-up facilities. Hospice is pain control. Hospice is skilled nursing. Hospice is a doctor and a clergyman coming to your home...But most of all, hospice is the humanization of our health care system.” –

Senator Edward Kennedy, 1978

Training in hospice and palliative medicine involves “skilled communication with patients and families in the context of serious illness, safe and effective symptom management, and psychosocial assessment and support”, which many U.S. physicians lack. Yet, financial support for such training depends predominantly on philanthropy rather than Medicare-funded graduate medical education (GME) dollars. This shortage in training and funding also exists in other fundamental disciplines of a hospice team: nursing, social work, and chaplaincy. Increased training and organized financial support can extend the benefits of hospice care to those who have little knowledge or who are unaware of it.⁷² A bill currently under consideration in

the Congress will help address the shortage in training and funding. HR 647, The Palliative Care and Hospice Education and Training Act (PCHETA) addresses a shortage in the healthcare workforce focusing on hospice and palliative care by establishing Palliative Care and Hospice Education Centers, Expanding Palliative care Research, Providing Academic and Career incentive awards and establishing a national awareness campaign.

As the U.S. population ages and the number of Medicare eligible individuals grows, professionals trained in palliative care will continue to be in high demand. Age-related diseases such as Alzheimer’s disease are catching up to terminal cancer diagnoses as being top primary diagnoses for patients entering hospice care. The future of hospice depends on the specialized skills and expertise of professionals equipped to serve these patients and their families.

“The really important thing is meeting patients and families where they are and delivering the level of care that most effectively addresses their physical, psychosocial, and spiritual suffering. That may be palliative care, or it may be hospice. At best, it’s palliative care now, with a timely transition to hospice when curative care is no longer effective or desired.”

Jennifer Moore Ballentine, Executive Director CSU Institute for Palliative Care

⁷² Meier et al. A National Strategy for Palliative Care. *Health Affairs* 2017; 36(7):1265-1273.

Discussion: Policy Considerations for the Future

Summary

The purpose of this policy brief is to provide stakeholders with information on the history of hospice and the hospice value proposition. In so doing, the paper provides a context as well as a platform for dialogue concerning the above considerations. The following action items have been identified as opportunities for advancing the hospice value proposition:

- **Preserve the integrity of the hospice benefit as Medicare Advantage (MA) plans, ACOs and other organizational delivery forms as they expand in coming years**
 - Ensure CMMI accountability for transparency and inclusion of stakeholder feedback for MA VBID model and hospice, as well as the Alternative Payment Model for serious illness.
- **Concurrently coordinate the hospice benefit with medical and psychological care under all Medicare payment models**
 - Develop legislation that will provide patients and families living with serious illness knowledge and access to information and services. Direct CMMI to conduct a demonstration that will allow an interdisciplinary team to provide home-based palliative care services and assistance in developing goals of care and treatment options, as well as advance care planning.
- **Expand timely access to hospice and palliative care based on the individual's unique care needs**
 - Re-introduce and enact the *Rural Access to Hospice* (S. 980/H.R. 1828 in 115th Congress) legislation to allow physicians and other non-physician practitioners in Rural Health Clinics and Federally Qualified Health Centers to serve as a patient's attending physician when they elect hospice.
- **Ensure high-quality supply of hospice care providers and professionals who are poised to address the rapidly aging population seeking hospice and palliative care**
 - Enact PCHETA (H.R. 647) as bipartisan legislation in both the House and Senate to strengthen education and training opportunities for physicians and other practitioners.