

Nonprofit Hospice Services:

Where Mission and Community Meet

April 2019



LeadingAge®

LeadingAge®
Ohio



National Partnership
for Hospice Innovation

ADVOCATING EXCELLENCE IN ADVANCED ILLNESS,
HOSPICE, AND PALLIATIVE CARE

Acknowledgements

This report was developed by staff at LeadingAge National, LeadingAge Ohio, and the National Partnership for Hospice Innovation. The final product reflects input and participation from a community of experts, including: Mollie Gurian, Ruth Katz, GERALYN Magan, Amanda Marr, John Richardson, and Susan Wallace.



“You matter because you are you and you matter to the last moment of your life.”

—Dame Cicely Saunders

Introduction

Dame Cicely Saunders, a British nurse and social worker, established what became the modern hospice movement in London in 1948.¹ Hospices provide expert medical, emotional and spiritual care and support—focusing on comfort and quality of life—to terminally ill patients and their caregivers. Typically, services are offered in the home, but they may be provided wherever the person calls home—whether that be an assisted living facility or a nursing home or any other type of residential facility. The Medicare Hospice Benefit was created as a pilot program in 1981 and fully incorporated into the Medicare program in 1983. It provides interdisciplinary team services that include medical, spiritual, personal care, volunteer and bereavement services for beneficiaries with a life expectancy of six months or less and their caregivers.

The purpose of this paper is to describe the benefits of the traditional, robust hospice model and point to differences between some newer providers and traditional community-based, nonprofit hospice providers. In doing so, we believe it will help to inform perspective on trends in the benefit and in health care over all. For example, while utilization of the Medicare Hospice Benefit has increased over time (fewer than half of Medicare decedents were enrolled in the hospice benefit in 2016), the number of beneficiaries who have a short length of stay on hospice is troubling (28% were on hospice for 7 days or less in 2016). Understanding the fundamentals of a robust hospice model informs why these trends cannot be looked at in vacuum. It is also valuable to study the way the hospice benefit is structured and delivered, because it can inform health and long-term services and supports system delivery reforms that have been taking place for the past decade. Hospice was one of the first benefits based on careful care coordination, an interdisciplinary approach and a capitated payment model.

The Medicare Payment Advisory Commission (MedPAC) has been watching hospice trends and recommending financing changes for the past several years. Notably, MedPAC commissioners have pointed to steep increases in hospice spending and the number of hospices concurrent with the substantial increase in the number of for-profit hospices. It is worth noting here that MedPAC Commissioners have commented that for-profit hospices typically have a higher margin than not for profit hospices. MedPAC and other observers, including the Centers for Medicare & Medicaid Services (CMS), have pointed out it is critical to ensure hospices are reimbursed appropriately but not overpaid. With this in mind, the way Medicare pays for hospice was changed in 2016, for the first time since the benefit was established.

At the same time, for the past decade, we have witnessed broad scale changes in the way health care delivery systems are structured and financed and the way health care is delivered in the U.S. Given these delivery system reforms focused on delivering high-quality care while saving taxpayer dollars and the changes in hospice reimbursement, LeadingAge (National and Ohio) and the National Partnership for Hospice Innovation believe it is essential to:

- Review the distinguishing characteristics of the hospice benefit.
- Point out the service array and quality differences across the spectrum of hospice providers.
- Note some differences in comparative growth of nonprofit and for-profit hospices.
- Remember that many of today's delivery system reforms are based on an interdisciplinary team model with close care coordination in a capitated environment – an approach the Medicare hospice benefit has used since it was established.

¹ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1179787/>

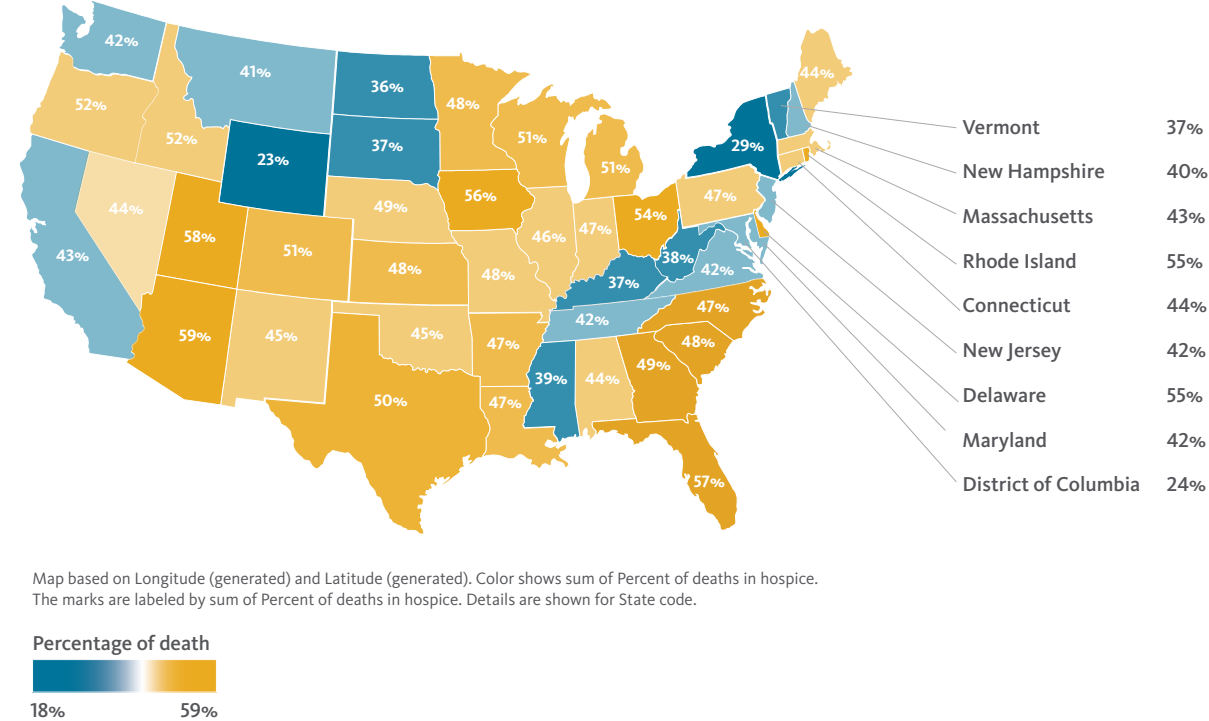
The Evolving Medicare Hospice Benefit

Hospice was the first capitated, interdisciplinary team-based model with psychosocial support for both the patient and family to be integrated into the Medicare program. Hospices must provide all care related to the patient's terminal condition, including nursing services, case management, medications and medical equipment (DME). Beyond medical services, hospices provide bereavement services, chaplaincy/spiritual services, medical social services and hospice aide services. They also coordinate a staff of volunteers in patient care roles. Until recent reforms, hospice was the only Medicare benefit that used this bundled model of care.

From its inception in 1983 through 2000, the Medicare Hospice Benefit grew steadily, but remained a relatively small part of the Medicare program. In the 2000's, however, the face of hospice changed dramatically, as the number of hospices ballooned from just over 2,200 in 2000, to 4,200 in 2016. Along the same timeframe, the number of for-profit programs also grew exponentially from 672 in 2000 to 2,938 in 2016.²

Hospice utilization varies across the United States, and in 2015 the percent of Medicare decedents who were receiving hospice at the time of death ranged from only 18% in Alaska to 59% in Arizona (Figure 1).

Figure 1: Percent of Medicare Decedents Who Died in Hospice



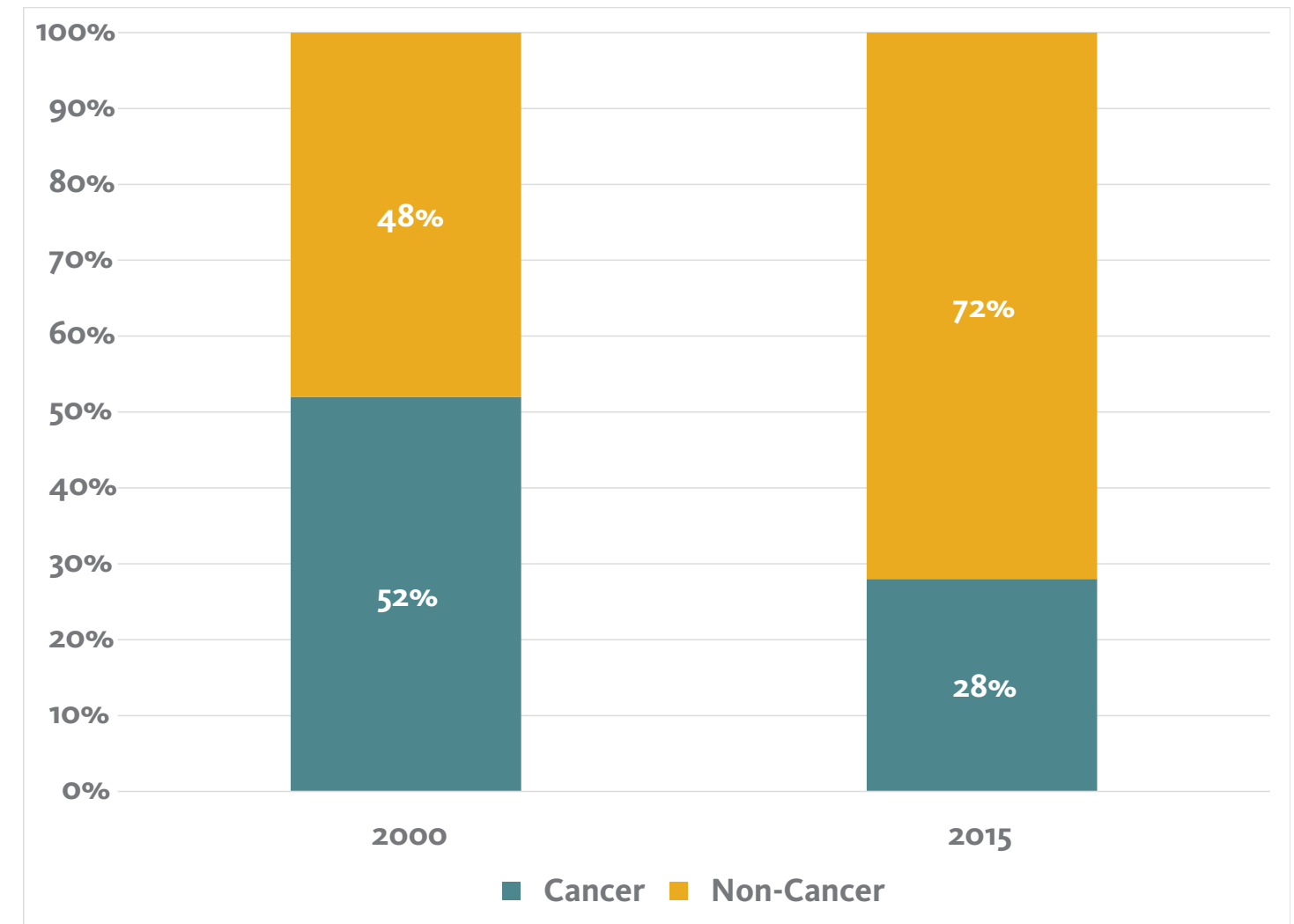
Over the same period of time, the hospice patient population has changed drastically: hospice is now serving more individuals residing in nursing homes and assisted living in addition to its traditional home-based population. In 2016, half of all Medicare hospice beneficiaries died at home and a third died in a nursing home.³ The terminal conditions experienced by hospice enrollees are also changing. Whereas hospices initially served primarily patients with cancer, they now serve individuals with many different diagnoses, including neurological conditions such as dementia, as well as progressive cardiac and pulmonary diseases (Figure 2).⁴

² http://medpac.gov/docs/default-source/reports/mar18_medpac_ch12_sec.pdf, pg. 330

³ Map graphic created by the National Partnership for Hospice Innovation based on the state-level hospice Medicare utilization file from 2016 accessed at <https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Medicare-Provider-Charge-Data/Hospice.html>

⁴ Change in Hospice Patient Diagnoses Graphic Data are from: https://www.nhpco.org/sites/default/files/public/Statistics_Research/2017_Facts_Figures.pdf

Figure 2. Change in Distribution of Hospice Patient Diagnoses from 2000 to 2015



How Medicare Pays for Hospice Services⁵

The Medicare program pays a daily rate to hospice providers, who assume all financial risk for costs and services associated with caring for the patient's terminal illness and related conditions. The hospice program is paid for each day the individual is enrolled, whether or not the program visits the client that day. This enables the program to cover other costs, such as palliation and management of the terminal condition plus "related services" such as care planning, on-call services, drugs, medical equipment, supplies and transportation.

Payments are made based on four levels of care, distinguished by intensity and setting of services:

- Routine Home Care, the most common (98% of all hospice days in 2016). With this type of care, the individual has elected to receive hospice care in his or her residence.
- Continuous Home Care (CHC). This care is provided for eight to 24 hours a day to manage pain and other acute medical symptoms. It is predominantly nursing care and maintains the person during a pain or symptom crisis.
- Inpatient Respite Care. This care provides temporary relief to caregivers by offering temporary care in a hospital, nursing home or hospice facility, where 24-hour nursing personnel are present.
- General Inpatient Care (GIC). This type of care is provided in a hospital, hospice or nursing home when pain or acute symptoms cannot be controlled at home.

⁵ http://medpac.gov/docs/default-source/reports/mar18_medpac_ch12_sec.pdf

CMS modified the rate structure for Routine Home Care in 2016, to recognize that the first 60 days of hospice use are more resource intensive. By day 61, the typical user requires fewer services and this low intensity continues until the last days before death. CMS reimburses for additional RN and social work visits in the last seven days of life, as patient needs typically increase again.

Closely related to payments, hospice length of stay is increasing, with an average of 87.8 days in 2016, up slightly from 86.7 days in 2015. The median stay increased during this period from 15 to 16 days. Nevertheless, more than one fourth of hospice decedents enroll in hospice only in the last week of life, a length of stay thought to be of less benefit to patients and their families than a longer stay. According to MedPAC, these short stays relate to:

- Physicians being reluctant to discuss hospice or delay such discussions until the patient is close to death;
- Some patients and families having trouble accepting a terminal prognosis;
- The requirement that patients forego intensive conventional care in order to enroll in hospice; and,
- Financial incentives in fee-for-service Medicare that encourage increased volume of clinical services.

Congress and CMS have introduced a number of initiatives to promote earlier hospice enrollments and better-quality end-of-life care.

How Medicare Measures Hospice Quality and Hospice Compare

The Patient Protection and Affordable Care Act mandated a Hospice Quality Reporting Program (HQRP) that required that all hospices submit data on quality measures. Medicare Hospice providers that do not submit data face a loss of 2% of the payment increase they would get for the year under Medicare. The law further required that CMS publicly report on quality measures related to the care provided by hospice programs across the country.

In 2017, CMS released the Hospice Compare website to help consumers compare hospice providers based on their reported quality data. The quality measures that are reported by hospices are based on consumer feedback from hospice patients and their family members on aspects of care, such as communication with family members, training family members to help with care, their rating of the hospice and their willingness to recommend the hospice provider.

Additionally, the hospice completes the “Hospice Item Set,” which includes information on how the hospice considers and addresses patient preferences, assessments and pain management.

Growth in the Number of For-Profit Hospices

The number of hospices in the US grew substantially between 2000 and 2015 from 2200 to 4200, as noted earlier. This rapid growth has been almost entirely due to entrance of for-profit hospices into the market, while the number of those that are nonprofit or government-sponsored has declined over the same period. According to MedPAC, in 2015, about 65% of hospices were for-profit, 31% were nonprofit, and 4% were government-owned (Figure 3). In 2016, the number of for-profit hospice providers grew by 7%.⁶

Figure 3. Growth in Number of Hospices by Ownership (Profit) Status from 2000 to 2015



Hospice is an attractive venture for private equity investors. Although mergers and acquisitions slowed during 2015-2017, they increased in 2017 along with overall growth in the industry. With increased consolidation trends and regulatory scrutiny, the number of not-for-profit providers is likely to decrease.

⁶ http://medpac.gov/docs/default-source/reports/mar18_medpac_ch12_sec.pdf.

Concerns Raised About Hospice Quality

During the period of rapid growth in the hospice sector, 2000-2016, regulators and the public have become increasingly concerned about fraud in the Medicare Hospice Benefit. In a 2014 *Washington Post* series titled “The Business of Dying,” investigators highlighted problem areas, including infrequent surveys⁷, problematic admission and discharge processes and unnecessarily burdensome care transitions⁸, failure to offer required crisis management services and inadequate care in the final days of life⁹.

Many of these problems were found more likely to be present in newer, for-profit hospices than in long-established, nonprofit hospices.¹⁰ Some research has even gone beyond suggesting an association and noted a positive correlation between live discharge rates (i.e., patients not dying when they use hospice), which is sometimes an indication of inappropriate hospice admission, and hospice profit margins.¹¹

Regulatory oversight agencies, including CMS, its contractors and the Office of the Inspector General (OIG) have responded to these concerns by increasing oversight of the Medicare Hospice Benefit. From 2011 to the present, hospices have experienced significant regulatory changes, including added requirements for face-to-face physician visits, modifications to reimbursement rates, claims-based data reporting requirements and quality reporting requirements. Some of these changes—such as standardized quality reporting—are welcomed by community-integrated, nonprofit hospices, provided the quality measures align with patient and family goals. Other changes, such as the requirement that patients have a face-to-face physician visit prior to recertifying their hospice eligibility, unnecessarily stretch the resources of these high-quality programs and redirect resources from other initiatives that would result in more care coordination and improvement. The lack of transparency regarding what the contractors are focused on also makes it difficult both to comply with and to understand the reasoning behind the current oversight structure.

Distinguishing Characteristics of Traditional Community-Integrated Hospices

Nonprofit hospices were pioneers in creating a new way of caring for Americans at the end of their lives. Many of these pioneers remain active in their communities today. Hospice care was the first all-inclusive, team-based model of care; hospice is the original community-based, patient-centered health care service. Hospice programs receive a capitated amount of funding to coordinate and deliver care to the patient and their caregivers. This section provides details about the essential elements that are the hallmarks of the most robust hospice care. It should be noted that most of the growth in hospice has been in the for-profit sector. While quality concerns have been raised by MedPAC and others, there is insufficient evidence to definitively point to differences between all for-profit and all nonprofit hospice providers. However, most long-standing, traditional, community hospice programs are nonprofit.

7 Whoriskey, P. “Is that hospice safe? Infrequent inspections make it difficult to know.” *Washington Post*. (June 26, 2014). Accessed September 2, 2017 from https://www.washingtonpost.com/business/economy/is-that-hospice-safe-infrequent-inspections-means-it-may-be-impossible-to-know/2014/06/26/e258e880-eaa4-11e3-b98c-72cef4a00499_story.html?utm_term=.dc82280dc86b.

8 Whoriskey, P. and Keating, D. “Rising rates of hospice discharge in US raise questions about quality of care.” *Washington Post*. (August 6, 2014). Accessed September 2, 2017 from https://www.washingtonpost.com/business/economy/leaving-hospice-care-alive-rising-rates-of-live-discharge-in-the-us-raise-questions-about-quality-of-care/2014/08/06/13a4e7a0-175e-11e4-9e3b-7f2f110c6265_story.html?utm_term=.e273e030bd6c.

9 Whoriskey, P. and Keating, D. “Terminal neglect? How some hospices decline to treat the dying.” *Washington Post*. (May 3, 2014). Accessed September 2, 2017 from https://www.washingtonpost.com/business/economy/terminal-neglect-how-some-hospices-fail-the-dying/2014/05/03/7d3ac8ce-b8ef-11e3-96ae-f2c36d2b1245_story.html?utm_term=.71bbfc591f50.

10 Whoriskey, P. and Keating, D. “Dying and profits: the evolution of hospice.” *Washington Post*. (December 26, 2014). Accessed September 2, 2017 from https://www.washingtonpost.com/business/economy/2014/12/26/a7d90438-692f-11e4-b053-65cea7903f2e_story.html?utm_term=.8cb76e2e9248.

11 Dolin, R., Holmes, G.M., Stearns, S.C., Kirk, D.A., Hanson, L.C., Taylor Jr., D.H., Silberman, P. (2010) A positive association between hospice profit margin and the rate at which patients are discharged before death. *Health Affairs*, 7, 1291-1298.

Deep Community Relationships

Over decades of service, many nonprofit hospice programs have built longstanding relationships with local health systems, schools, government agencies, churches and clergy, community service organizations and other partners. The senior leaders of these hospices often sit on the governing boards of other local community organizations, and reciprocally, these same organizations are represented in each hospice’s governance. This civic engagement and sharing of leadership, ideas and resources facilitates innovation and partnerships that are tailored to each community’s unique needs.

Robust Bereavement Support

Medicare does not reimburse for bereavement support, which is delivered to family members in preparation for and after an individual’s death (for 13 months). However, this support is required by hospice regulations and is a unique and crucial function of the Medicare hospice benefit.

Because bereavement support is not reimbursed, hospices attempting to cut costs may see it as an easy place to limit services. For example, a hospice may choose to send a letter with a phone number for bereavement care or ask social workers to assume bereavement responsibilities rather than employ a bereavement counselor to meet with and support families. Some hospices may even refer the families of their patients to other hospice programs for bereavement support, which circumvents their responsibilities and increases burden on hospices that do offer robust bereavement services.

Nonprofit, community-integrated hospices have been shown to be more likely than their for-profit counterparts to provide certain bereavement services, such as support groups and workshops, and to offer services to the community.^{12,13} Many nonprofit, community-integrated hospice programs provide services, such as group therapy, one-on-one grief counseling and specialized programs like grief camps for children. These hospices often serve as first responders for trauma in their communities, regardless of whether the recipients of the grief support or trauma counseling services have family members who utilized the hospice program. For example, a school that experiences the sudden death of a student may rely on its local hospice to meet with grieving staff and students.

Use of Volunteers

Hospice is the only Medicare benefit that requires community volunteers to deliver a significant portion of patient care hours. Medicare sets a 5% threshold for volunteer involvement, and many programs struggle to meet this threshold nor is it well enforced despite being a condition of participation.

Nonprofit hospices are leaders in using volunteers. They often expand the typical volunteer role by creating specialty volunteer-driven programs tailored to the needs of patients and families. These programs include:

- Veteran-to-veteran programs that match patients who have served in the military with volunteers who have also served;
- Pet therapy teams, in which registered animals and handlers visit hospice patients to provide companionship; and
- Vigil programs, which provide around-the-clock care for patients in the final hours of life.

One study noted that, compared to nonprofit hospices, for-profit and government-owned hospices used proportionally fewer volunteer full-time equivalencies as a proportion of total staff.¹⁴ Volunteers are valuable members of the hospice team, and their inclusion ensures hospice programs have ongoing integration with their local communities.

12 Foliart, DE., Clausen, M, Siljeström, C. (2001). Bereavement practices among California hospices: results of a statewide survey. *Death Studies*, 25(5), 461-467.

13 Barry, C. L., Carlson, M. D. A., Thompson, J. W., Schlesinger, M., McCorkle, R., Kasl, S., & Bradley, E. H. (2012). Caring for Grieving Family Members: Results from a National Hospice Survey. *Medical Care*, 50(7), 578–584. <http://doi.org/10.1097/MLR.0b013e318248661d>.

14 Cherlin, E.J., Carlson, M.D., Herrin, J., Schulman-Green, D., Barry, C.L., McCorkle, R., Johnson-Hurzeler, R., Bradley, E.H. Interdisciplinary Staffing Patterns: Do For-Profit and Nonprofit Hospices Differ? *Journal of Palliative Medicine*. (April 2010). 13(4): 389-394.

Prudent Use of Levels of Care

Every hospice patient will not need all four levels of care described earlier in this report. However, hospices providing all 4 levels is an indicator of quality and hospices must be prepared in terms of staffing, contracts and other resources, to offer each level according to a patient's needs. In a 2014 report, Abt Associates noted that roughly a quarter of hospices nationwide provided no general inpatient care during the study period, and more than half of hospices provided no CHC care during the same period. Hospices more likely to provide GIP care were older (in operation for 20 or more years), larger, and located in the Northeast.¹⁵ A subsequent OIG report found that hospices that did not provide GIP were more likely to be for profit.¹⁶ These findings suggest that community-integrated, nonprofit hospices are more likely to meet patient needs with multiple levels of care.

Specialized Programming for Patients with Complex Care Needs

Nonprofit, community-integrated hospices provide care regardless of location, complexity or diagnosis. Because these hospices maintain highly-trained staff and deep community relationships, they are better equipped to care for patients and families who have particularly complex care needs, which may include multiple diagnoses, complicated family dynamics, or the absence of a caregiver. Many of these hospices offer a combination of services to support those dealing with serious illness outside of the parameters of the hospice benefit, including comprehensive, coordinated programs designed to meet the complex and multifaceted needs and goals of patients and families in their communities.

Other healthcare providers, including hospitals, recognize the unique ability of hospices to navigate complicated cases. Some upstream providers have established referral networks and other specialized programming to ensure these patients will receive the array of services they need. These types of programs include palliative care, disease-specific programming, transitions programs, and other services to make sure that patients with serious illness and their families get the supportive care they need in the place they call home.

Palliative Care Programs

Many community-integrated, nonprofit hospice providers offer palliative care in the hospital, in clinics, in other provider settings and/or in the home. Palliative care provides pain and symptom management for patients who have serious illnesses, helps them set goals and understand decisions, provides family and caregiver support, assists in care coordination, and offers practical and social supports. Research has shown that palliative care improves patients' quality of life and lowers health care costs, and that earlier use can reduce the need for crisis care.¹⁷

Despite these benefits, funding for palliative services is limited. Medicare Part B benefits may cover some palliative care services and medications¹⁸, but only palliative care prescriber services are billable in the outpatient setting. This payment practice excludes other members of the interdisciplinary team from providing palliative care.¹⁹ Some palliative care programs are working with private payers to move toward a population health model through which payment is made on a per patient per month basis. This new payment arrangement should better support the interdisciplinary team.

15 Abt Associates. *Medicare Hospice Payment Reform: Analyses to Support Payment Reform*. (May 2014). Accessed September 2, 2017 at <https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/Hospice/Downloads/May-2014-AnalysesToSupportPaymentReform.pdf>.

16 Department of Health and Human Services, Office of Inspector General. *Memorandum Report: Medicare Hospice : Use of General Inpatient Care*. OEI-02-10-00490. (May 2013). Accessed August 28 from <https://oig.hhs.gov/oei/reports/oei-02-10-00490.pdf>.

17 Morrison, R.S., Dietrich, J., Ladwig, S., Quill, T., Sacco, J., Tangeman, J., & Meier, D.E. Palliative care consultation teams cut hospital costs for Medicaid beneficiaries. *Health Affairs*. (2011). 30(3), 454-463.

18 American Academy of Hospice and Palliative Medicine. Frequently Asked Questions About Hospice and Palliative Care. Accessed October 17, 2015 at <http://palliativedoctors.org/faq>.

19 Kelley, A.S. and Meier, D.E. The Current and Potential Role of Palliative Care for the Medicare Population. *Generations: Journal of the American Society on Aging*. (2015).

A 2012 study found that nonprofit hospices were more than twice as likely to offer palliative care services to non-hospice patients than for-profit hospices.²⁰ This results in greater access to a broad array of needed services among patients, including those with high-cost or complex medical needs. In the current environment, many nonprofit providers report losing money on palliative care, which they continue to see as an important service for a population in need.

Pediatric Hospice and Palliative Care

Children make up approximately 2% of all deaths, with more than 50,000 dying each year in the U.S.²¹ The American Academy of Pediatrics recommends that palliative care be offered at diagnosis and continue throughout a child's illness, regardless of whether illness ends in a cure or death.²² In many communities, nonprofit hospices have partnered with local children's hospitals to address the needs of gravely ill children and their families, helping to either establish palliative care programs within hospital walls or ease the transition once families are ready to begin hospice care. The struggles families of terminally ill children face include the following:

- Families are less willing to relinquish aggressive treatments as they approach the child's end of life, instead opting to try any treatment that may offer even the slightest promise.
- Pediatric patients respond differently to medications and other treatments than adults, requiring specialized knowledge and skills.
- Navigating family dynamics is more complex, making psychosocial support more critical and more challenging to provide.
- Families of terminally ill children are more likely to have complicated bereavement experiences.

Caring for pediatric palliative patients requires significant specialized expertise and resources and is something that community-integrated, nonprofit hospices are uniquely qualified to do because of their deep community ties, robust bereavement services and advanced staff training. A 2009 study found that nearly 80% of hospice organizations that admit children and youth are not for profit.²³ Many hospice providers with robust pediatric programs also work with federally supported state waiver programs to provide coordinated care for the psycho-social and developmental needs of the child in addition to the medical needs.

20 Carlson, M.D., Aldridge, Barry, C.L., Cherlin, E.J., McCorkle, R. & Bradley, E.H. Hospices' Enrollment Policies May Contribute To Underuse Of Hospice Care In The United States" *Health Affairs*. (2012). Accessed August 25, 2017 at <http://content.healthaffairs.org/content/31/12/2690o>.

21 National Center for Health Statistics report *Deaths: Final Data 1999* (NCHS, 2001).

22 Committee on Bioethics and Committee on Hospital Care. Palliative Care for Children. *Pediatrics* (2000). 106(2). Accessed September 2, 2017 at <http://pediatrics.aappublications.org/content/106/2/351>.

23 Lindley, L., Mark, B., & Lee, S.-Y. D. (2009). Providing hospice care to children and young adults: A descriptive study of end-of-life organizations. *Journal of Hospice and Palliative Nursing: JHPN : The Official Journal of the Hospice and Palliative Nurses Association*, (2009) 11(6), 315-323. <http://doi.org/10.1097/NJH.0b013e3181bcfd62>.

Advanced Certification and Training

Many nonprofit, community-integrated hospices invest heavily in their staff, including allotting a substantial portion of their budgets to professional education and facilitating staff's advanced certification in hospice and palliative care. Currently, physicians may be board-certified in hospice and palliative medicine, and nurses, social workers, aides, and chaplains may be certified in hospice and palliative care.

Many national organizations, including the National Academies of Medicine, have called for increased certification and credentialing for nursing and other professions as a foundation for learning and means to improve quality of care and patient safety.²⁴ Additionally, "several studies have shown individual specialty certification has intrinsic value to nurses, increases the sense of empowerment and enhances collaboration with other members of the team."²⁵ A recent nationwide study found that nonprofit hospices provided far more training and research opportunities than for-profit hospices.²⁶

Room for Improvement in Hospice Policy

Medicare Hospice providers work hard to provide the highest quality, most cost-effective care possible. As noted earlier in this paper, Hospice payment policy has undergone some changes in recent years and hospice payment and service delivery policies are regularly discussed by members of MedPAC. In recent months, LeadingAge and the National Partnership for Hospice Innovation have supported and been pleased to see some key policy developments. These include:

- The Bipartisan Budget Act of 2018 changed the Social Security Act to recognize physician assistants as attending physicians for Medicare Hospice beneficiaries, in addition to physicians and nurse practitioners.
- The 2019 Final Medicare Hospice Prospective Payment Rule, updating hospice wages and payments, and certain other policies, was published on August 1, 2018. It simplifies Hospice Compare data for consumers, improves transparency for patients and aims to provide a "meaningful framework" that focuses on core measurement issues and reduces paperwork.
- On September 20, 2018, CMS published a proposed rule, Medicare and Medicaid Programs: Proposed Regulatory Provisions to Promote Program Efficiency, Transparency and Burden Reduction. If finalized, the rule will streamline the hiring process for hospice providers, integrate information that enables hospice providers to demonstrate compliance with drug management requirements, remove the requirement that hospices have an individual on staff who has "specialty knowledge" of hospice medications, change documentation requirements related to controlled drugs and streamline training requirements when hospice providers serve individuals in skilled nursing facilities.
- Congress enacted the Opioid Crisis Response Act, which will enable hospices to "safely and properly dispose of controlled substances" after patients die. Opioid drugs are an important component of palliative and end-of-life care; but the nation faces an opioid crisis. Hospice providers have a role to play in preventing diversion and ensuring proper drug disposal, not only when patients die but when care plans change.
- The House of Representatives passed the Palliative Care Education and Training Act (PCHETA) in the 115th Congress and it has been reintroduced in the 116th. PCHETA would increase the availability and quality of care by establishing palliative care and hospice workforce training programs, creating a national education and awareness campaign about the benefits of palliative care and available services and supports, and enhancing research on improving the delivery of palliative care.

- Congress enacted the RAISE (the Recognize, Assist, Include, Support, and Engage) Family Caregivers' Act which requires the Secretary of Health and Human Services to develop, maintain and update a strategy to recognize and support family caregivers. The Administration for Community Living is beginning implementation of this strategy and both groups have nominated potential participants for the RAISE Act Advisory Council

Despite these recent gains, hospice providers still face some legislative and regulatory challenges in the areas of payment policy, staffing and paperwork requirements and quality reporting. Some of the topline policy priorities for hospice providers include:

- Making sure the upcoming expansion of the Value-Based Insurance Design (VBID) demonstration that includes hospice in the Medicare Advantage program starting in 2021 is designed in way that is thoughtful and ensures beneficiary and family access to the critical services offered by nonprofit, community-integrated hospice providers.
- Supporting the Patient Choice and Quality Care Act, which would ensure that patients and their family members have a full understanding of their care options when they have advanced illness. The proposed legislation would promote the development of advance directives and ensure they are honored. Finally, it would provide resources to develop more robust quality measures for hospice and palliative care.
- Supporting the Rural Access to Hospice Act, which would allow Medicare payment for services furnished to hospice patients by rural health clinics and Federally Qualified Health Centers (FQHCs). Hospice care is underused in rural communities; one barrier is that physicians in rural health clinics, and FQHCs are not able to be part of the hospice team. This bill would change that.
- Work with legislators or U.S. Department of Labor officials to carve out a companionship exemption to the Fair Labor Standards Act (FLSA). Regulations issued in 2013 removed a longstanding exemption to the FLSA that recognized the unique nature of home care focused on older individuals in their own homes. These regulations add costs to home care, including hospice services, and may reduce the hours workers are available.
- Focus on aligning hospice program integrity efforts with high quality hospice care.
- Continue the work that has been done on innovating in the telehealth space and expand its applicability to hospice providers.

Conclusion

Nonprofit, community-integrated hospices benefit their patients, patient families and their communities in unique and recognizable ways. Nevertheless, hospice providers face some barriers that lawmakers and regulators could address or eliminate. By supporting nonprofit, community-based hospices and the services they offer, policymakers and other payers will not only support the survival of these hospices but raise the bar for high-quality hospice care for all patients, families and communities across the U.S. Hospice providers, families who benefit from comprehensive hospice services, and other advocates and stakeholders, must continue to educate policymakers and decision makers about the value of their work.

24 Hickey, J.V., Unruh, L.Y., Newhouse, R.P., Koithan, M., Johantgen, M., Hughes, R.G., & Lundmark, V.A.. Credentialing: The need for a national research agenda. *Nursing Outlook*, (2014), 62(2). pp. 119-127.

25 Hickey, J.V., Unruh, L.Y., Newhouse, R.P., Koithan, M., Johantgen, M., Hughes, R.G., & Lundmark, V.A. Credentialing: The need for a national research agenda. *Nursing Outlook*, (2014), 62(2). pp. 119-127.

26 Aldridge, M.D., Schlesinger, M., Barry, C.L., Morrison, R.S., McCorkle, R., Hurzeler, R., Bradley, E.H. National hospice survey results: for-profit status, community engagement, and service. *JAMA Internal Medicine*. (April 2014). 174(4). pp. 500-506.