FINAL REPORT
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Value of Hospice in Medicare

Presented by:
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Executive Summary

The National Association for Home Care & Hospice (NAHC) and the National Hospice and Palliative Care Organization (NHPCO) commissioned NORC at the University of Chicago (NORC) to assess the value of hospice to the Medicare program and to beneficiaries, their families, and caregivers.

Background and project goals: Increases in Medicare’s hospice benefit enrollment (16.5 percent) and spending (31 percent) from 2015 to 2019 have garnered policymaker attention to hospice and led the Medicare Payment Advisory Commission (MedPAC) to recommend that FY 2023 Medicare base payment rates for hospice remain at 2022 levels, and that the hospice aggregate cap should be wage-adjusted and reduced by 20%. These recommendations amount to a decrease in hospice spending by $250 million–$750 million over one year (approximately 1-3 percent of Medicare hospice outlays) and $5 billion–$10 billion over five years.

This study seeks to estimate the value of the Medicare hospice benefit for patients with terminal conditions, their families, and caregivers, as well as its impact on Medicare spending. Moreover, the analysis explores opportunities for policy makers and hospice organizations to further refine the hospice benefit to ensure it continues to support patients nearing end of life, as well as their families and caregivers.

Approach: NORC assessed the value of Medicare’s hospice benefit by primarily using administrative claims data to estimate beneficiary utilization and the impact of hospice use on Medicare spending. NORC compared the outcomes of Medicare beneficiaries who had a hospice stay immediately prior to death to Medicare decedents who did not have a hospice stay but otherwise had a similar risk profile. Differences in chronic health status, end-of-life (EOL) diagnoses, and demographics between the two populations were addressed with a propensity weight model.

Key findings:

- In the last year of life, the total costs of care for Medicare beneficiaries who used hospice was 3.1 percent lower than the adjusted spending of beneficiaries who did not use hospice. This relatively modest reduction in adjusted Medicare spending translates to an estimated $3.5 billion less in Medicare outlays for beneficiaries in their last year of life.

- Examination of Medicare spending in policy-relevant length of stay groupings (0-14 days, 15-30, 31-60, etc.) found that total Medicare spending in the 12 months preceding death is consistently lower for beneficiaries with LOS of 15 days or more, compared to beneficiaries who did not use hospice, regardless of disease group.

- Furthermore, analyses to find the specific day when Medicare spending for non-hospice users equals spending for hospice users—revealed the “break-even” point at day 10. Starting on day 11 (prior to death), hospice users’ Medicare spending is lower compared to spending for non-
hospice users. In other words, earlier enrollment in hospice—and longer lengths of stay—may reduce Medicare spending.

• **Hospice stays of six months or more add value to Medicare.** For those who spent at least 6 months in hospice in the last year of their lives, spending was 11 percent lower than the adjusted spending of beneficiaries who did not use hospice. When sorted by disease group, spending ranged from being 4 percent lower for neurodegenerative disease to 25 percent lower for chronic kidney disease/end stage renal disease (CKD/ESRD).

• **Hospice care benefits patients, family members, and caregivers.** From increased satisfaction and quality of life, to improved pain control, to reduced physical and emotional distress, and reduced prolonged grief and other emotional distress, hospice offers multiple benefits to patient, families, and caregivers.
Background

In 1963, Dame Cicely Saunders—an English nurse, social worker, physician, writer, and founder of the first modern hospice—introduced the idea of specialized care for the dying to the United States in a lecture at Yale University. The idea took root, leading to U.S. Senate hearings on “Death With Dignity”, national symposiums and conferences, print and multimedia advocacy efforts, demonstration programs, and initial regulations and accreditation standards. It took almost two decades from that Yale lecture for hospice to be added as a Medicare benefit in the Tax Equity and Fiscal Responsibility Act of 1982. In 1983, initial Medicare Hospice Regulations establishing four levels of hospice care were published in the Federal Register. Two years later, the Consolidation Omnibus Budget Reconciliation Act of 1985 made the Medicare hospice benefit permanent.

Medicare’s hospice benefit is designed as a per diem “comprehensive, holistic program of care and support for terminally ill patients and their families [which] changes the focus to comfort care [palliative care] for pain relief and symptom management instead of care to cure the patient’s illness.” It also may be extended indefinitely as practitioners recertify patient need for hospice.

People with Medicare coverage for hospital insurance—referred to as Medicare Part A—can get hospice benefits if they receive care from a Medicare-certified hospice and have two physicians (the patient’s attending physician, if there is one, and the hospice medical director) certify them as terminally ill with a medical prognosis of six months or less to live. When a patient chooses hospice care, they waive their rights to Medicare coverage of disease-focused curative treatments for their terminal illness. However, treatments and services to reduce pain or symptom severity, and manage the terminal illness and related conditions, are included in the hospice benefit.

In 2019, 1.61 million Medicare beneficiaries were enrolled in hospice care for at least one day. This represents a 4 percent increase from 2018 and a steeper 16.5 percent increase from 2015. In 2019, Medicare spending on hospice was $20.9 billion, representing an 8.5 percent increase from 2018 and a 31 percent increase from 2015. This growth in hospice enrollment and spending coincided with a decade in which Congress passed the Affordable Care Act and as policy makers carefully examine and propose other cost-cutting measures such as encouraging providers to deliver lower-cost yet higher-quality medical services that meet person-centered needs.

2 National Hospice and Palliative Care Organization, “History of Hospice.”
3 “Hospice | CMS.”
4 The hospice benefit is designed with benefit periods wherein the beneficiary’s enrollment in the Medicare hospice benefit is confirmed and recertified. Currently there are two benefit periods of 90 days each, followed by an unlimited number of 60 day benefits. The benefit may be extended at the beginning of each benefit period if the hospice medical director confirms the continued need for hospice care and recertifies the continuation of hospice care.
6 Adjusted for inflation (CPI Inflation Calculator), hospice spending growth from 2015-2018 is 7 percent and growth from 2015-2019 is 22 percent.
Due to increased scrutiny on hospice’s growing enrollment and spending, MedPAC’s—an independent congressional Medicare advisory agency—March 2022 Report to Congress contained specific recommendations to curtail hospice spending. The report recommended that FY 2023 Medicare base payment rates for hospice remain at 2022 levels, and that the hospice aggregate cap should be wage-adjusted and reduced by 20 percent. MedPAC estimated that this would lead to a cost savings of between $250 million and $750 million over one year, and $5 billion and $10 billion over five years.

Concerned about the potential negative consequences of these recommendations on the millions of Medicare beneficiaries who need specialized end-of-life care, NAHC and NHPCO commissioned NORC with quantifying the value of hospice. This study examines hospice utilization, its impact on Medicare spending, and its benefit to patients, their families, and caregivers.

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7 This recommendation was first published in the March 2020 MedPAC Report to Congress, Hospice chapter
Brief Research Methodology

NORC used The Centers for Medicare & Medicaid Services (CMS) administrative claims, encounters, and enrollment files to observe health care utilization and define subgroups of interest from 2016-2019 data on the 2.3 million Medicare beneficiaries who died in 2019. Researchers employed ICD-10-CM diagnosis codes to sort these beneficiaries into five subgroups representing common EOL diseases—cancer, circulatory disease, neurodegenerative disease, respiratory disease, and CKD/ESRD. NORC calculated Medicare total costs of care (referred to as “Medicare spending”) and utilization of services in the time leading up to death—the “lookback period”—for the decedent’s last 12 months of life, beginning at beneficiary’s date of death. For Medicare beneficiaries who did not use hospice in their last year of life, researchers adjusted their total costs of care for this final year using a propensity weighting model.

The model used each beneficiary’s demographic characteristics, as well as chronic conditions, to determine their likelihood, or appropriateness, of using hospice care and based on the beneficiary’s risk profile and appropriateness for hospice, each person was assigned a relative “weight.” The more likely an individual was to use hospice, the greater their relative weight. Utilization and spending were aggregated and weighted by a summary of the beneficiaries’ relative weights to ensure that NORC selected the most appropriate comparison group for this study.

Moreover, the analysis further segmented utilization and spending measures by whether services were provided prior to the hospice stay (“non-concurrent”) or concurrent to the hospice stay but billed separately from the hospice benefit (“non-hospice concurrent”). The primary focus of this report is the findings from the 12-month lookback period. The analysis of Medicare spending is limited to decedents who were continuously enrolled in traditional Medicare Fee-for-Service (FFS) during this period.
Value of Hospice in Medicare

Findings

Impact on Medicare Spending

NORC analyzed the value of hospice to the Medicare program by comparing spending of Medicare beneficiaries who used hospice (hospice users) to a group of Medicare beneficiaries who did not use hospice (“No Hospice Days”). The analysis was based on the 12-month lookback period prior to beneficiaries’ deaths in 2019.

NORC discovered that in their last year of life, the total costs of care for Medicare-enrolled hospice users was 3.1 percent lower than the adjusted spending of beneficiaries who did not use hospice. However, spending varied significantly across disease groups with values ranging from 2.9 percent higher to 7.6 percent lower, for neurodegenerative disease and CKD/ESRD, respectively (Figure 1).

Figure 1. Comparison of Total Costs of Care (TCOC) by Disease Group in the 12-Month Period Before Death
On average, hospice episodes that fall into LOS groupings of 15 days or longer are associated with lower total costs of care for hospice users than non-hospice users. The relative value of hospice for Medicare tends to increase as hospice episodes lengthen, since the hospice benefit replaces more costly, curative, or interventional treatment. These findings are generally consistent across all disease groups, with a small exception for cancer patients whose lengths of stay (LOS) in hospice are 15–30 days (Figure 2).

Although Medicare total costs of care are lower across almost all disease groups, the difference between hospice users and “No Hospice Days” varies widely across disease groups and hospice stay lengths, especially those greater than 266 days. The difference tends to increase as hospice stays lengthen, around 91–180 days, at which point relative value tends to flatten (Figure 2).

Figure 2. Comparison of Total Costs of Care by Disease Group & Hospice Episode LOS in the 12-Month Period Before Death

Figure 2, above, shows that when the hospice stays were less than 15 days, total Medicare spending for hospice users was greater than total spending for beneficiaries who did not use hospice. Overall, almost half (49.5 percent) of hospice users were enrolled in hospice for less than 15 days. The high proportion of beneficiaries in this LOS group coupled with higher total costs of care for hospice users (with the exception of beneficiaries who have respiratory disease) prompted a deeper investigation into

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9 Beneficiaries whose death date was at least seven days after discharge from their final hospice stay were considered to be “live hospice discharges” and were excluded from NORC analyses. These beneficiaries were excluded so as to produce a study group whose hospice experience best reflected the benefit’s intended outcome (if beneficiaries are discharged from hospice, expiration should likely occur soon thereafter); Hospice LOS of 266 days represents the 90th percentile cutoff per MedPAC July 2021 data book (CY 2019).

10 See appendix table 1 for beneficiary counts by disease group and hospice length of stay.
stays that were 15 days or fewer to understand the specific day on which spending value begins to appear. NORC analyzed these short stays to reveal a break-even point, by disease group and overall.

To conduct this analysis, beneficiaries who used hospice were further grouped by day based on their specific hospice LOS. NORC calculated each group’s average total costs of care, and sums were compared against the total costs of care for the “No Hospice Days” cohort. This break-even point is the specific LOS (number of days) when Medicare spending for non-hospice users is approximately equal to spending for hospice users.

**NORC’s analysis reveals an overall break-even LOS of 10 days, meaning that stays of 11 or more days generate greater value.** By disease group, beneficiaries with respiratory disease see a break-even point on day 3. By contrast, beneficiaries with cancer have a longer break-even point at 17 days, likely due to the difference in interventional treatment costs (Figure 3).

Our findings suggest that earlier enrollment in hospice—translating into longer LOS—has the potential to generate additional spending value for Medicare.

**Figure 3.** Comparison of Total Costs of Care Break-Even Point by Hospice Days\(^\text{11}\)

For hospice stays that were greater than 180 days (6 months), researchers found that the total costs of care for hospice users in the year prior to death were 11 percent lower per person, on average, than those of non-hospice users. For hospice stays between 181–266 days, the proportion of the total costs of care attributed to hospice reaches 60 percent, yet the total costs of care are still almost $7,000 less than that of non-hospice users, $60,289 and $67,192 respectively (Figure 4).

Furthermore, when hospice stays extend beyond 266 days, and hospice spending accounts for almost 90 percent of the total Medicare bill, total costs of care for hospice users are approximately $8,000 less than that of non-hospice users.

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\(^{11}\) Example interpretation: Respiratory hospice users’ 12-month TCOC was greater than non-hospice users for LOS of 1 and 2 days, breaks-even at 3 days, and is lower than non-hospice users for lengths of stay of 4 days or more.
These findings further point to the hypothesis that enrollment in hospice lowers overall Medicare spending by substituting hospice care for alternative high-cost EOL treatment.

**Figure 4.** Comparison of Total Costs of Care (TCOC) by Hospice Episode LOS in the 12-month Period Before Death

Although average total costs of care were 11 percent lower for hospice users with 180+ day stays than non-hospice users, this varied significantly across disease groups. *Medicare beneficiaries with CKD/ESRD who used hospice had the greatest difference (25%) compared with beneficiaries who did not use hospice*, followed closely by beneficiaries with respiratory disease (20 percent). However, hospice users with neurodegenerative disease exhibited a modest 4 percent difference (Figure 5).

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12 Hospice = Medicare spending on hospice care while the hospice benefit was elected; Non-Hospice Concurrent = Medicare spending on any/all non-hospice health services that occurred while the hospice benefit was elected; Non-Concurrent = Medicare spending on any/all non-hospice health services that occurred when the hospice benefit had not been elected.
Figure 5. Comparison of Total Costs of Care (TCOC) Difference by Disease Group for Hospice Stays Greater than 180 Days

LOS > 180 Days TCOC Difference (%) from Non-Hospice Users

-5.0%
-10.0%
-15.0%
-20.0%
-25.0%
-30.0%

- All Disease Groups -11.0%
- Circulatory -9.0%
- Neurodegenerative -4.0%
- Cancer -17.5%
- Respiratory -20.0%
- CKD/ESRD -25.0%

Spending is greater than non-hospice users
Spending is less than non-hospice users
No Difference/Not Statistically Significant

Value of Hospice to Patients, Families & Caregivers

The final years and days of life can be extremely difficult and stressful for patients, their loved ones, and their caregivers—who can often be one and the same—warranting a closer examination of what the experience of hospice entails. To understand the value of hospice care to them, NORC examined peer-reviewed studies of their EOL experiences.

Researchers found that patients who entered hospice care toward the end of their lives reported greater satisfaction, better quality of life, and reduced physical and emotional distress. Specifically, recent research shows that hospice admissions in the last six months of life correlate not just with increases in patient satisfaction, but with better pain control, fewer hospital days, and fewer deaths in the hospital including with an intensive care unit (ICU) admission.13

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13 Kleinpell et al., “Exploring the Association of Hospice Care on Patient Experience and Outcomes of Care.”
Hospice care also appears to strongly benefit people with dementia. A 2022 study leveraged nationally representative data from the National Health and Aging Trends Study and Medicare claims to examine whether and how perceived quality of care in the last month of life differed between people with and without dementia, and if hospice care had an impact. Researchers found that those with dementia who were enrolled in hospice had a higher perceived quality of care compared to those outside of hospice. These findings argue for improved access to hospice for this group.

An October 2010 prospective, longitudinal, multisite study of patients with advanced cancer and their caregivers sought to determine whether the location where cancer patients died is associated with their Quality of Life (QOL) at the EOL. Findings indicate that those who died in an ICU or hospital experienced more physical and emotional distress and worse QOL at the end compared to patients who died at home with hospice. This study also assessed the effects of site of death on the emotional distress of caregivers. Findings show that ICU deaths were associated with a higher risk of caregiver post-traumatic stress disorder than home hospice deaths. Similarly, hospital deaths were associated with a greater risk for prolonged grief disorder compared to home hospice deaths.

Family members and caregivers of hospice users also benefit from perceptions of improved patient care and reduced risk of emotional and psychological distress. A 2017 Journal of Clinical Oncology study revealed that the families of hospice users believed that patients’ EOL wishes were followed and rated the quality of EOL care as “excellent,” more often than their non-hospice counterparts. Although family members reported that their loved ones seemed to experience more pain compared to those not in hospice care, they also remarked that hospice provided “just the right amount” of pain medicine and help with dyspnea. Family members of 30+ day hospice users reported the most positive EOL outcomes.

In sum, patients, family members, and caregivers experience the value of hospice through increased satisfaction and quality of life, improved pain control, reduced physical and emotional distress (patients), and reduced prolonged grief disorder and other emotional distress (family/caregivers).

14 Harrison et al., “Hospice Improves Care Quality For Older Adults With Dementia In Their Last Month Of Life.”
15 Wright et al., “Place of Death: Correlations With Quality of Life of Patients…Mental Health.”
16 Kumar et al., “Family Perspectives on Hospice Care Experiences of Patients with Cancer.”
Conclusion

Of the 2.3 million 2019 Medicare beneficiary decedents, NORC analyzed utilization of health services and costs of care for the last 12 months of life for 960,000 FFS beneficiaries. This sample includes just over 500,000 people who used hospice prior to death, illustrating the value of hospice in lowering Medicare spending and corroborates prior research findings that hospice care not only improves the quality of life for patients but also of their families and caregivers.

Critically, this claims-based analysis demonstrates that hospice care is a cost-effective option for Medicare beneficiaries in their last year of life, regardless of terminal condition and when their LOS falls into any of the groupings longer than 15 days. Drilling down into the short and long tails of hospice LOS reveals that hospice spending first breaks even at day 10, and that spending value persists through very long (180+ days) hospice stays.

In addition, this study confirms that hospice care adds value to patients, family members, and caregivers by increasing satisfaction and quality of life, improving pain control, and reducing both physical and emotional distress in patients and prolonged grief and other emotional distress in their family and caregivers.

While conducting this research, NORC identified several areas that warrant further exploration. First, it would be useful to model both the proportion of non-hospice user decedents who might be eligible for hospice as well as which short-stay hospice users might be brought into hospice earlier. Second, this project produced measures of utilization that include Medicare Advantage (MA) enrollees. These measures can be used to further investigate how MA enrollment impacts the likelihood that enrollees will enter hospice, and utilization characteristics such as LOS. Lastly, there is a substantial opportunity to further explore what health care utilization, diagnoses, and changing frailty represent for mortality risk and prediction of hospice use.

Implications for Medicare Outlays

NORC’s quantitative analysis focused on estimating the value of hospice on utilization of health care services and total costs of care for Medicare beneficiaries. Based on the findings that, on average, the hospice benefit was associated with a difference of 3.1 percent in total costs of care between hospice users and non-hospice users, NORC performed a crude calculation to extrapolate the findings to generate a cumulative impact to Medicare outlays. The 3.1 percent in potential savings that NORC calculated in this analysis applies only to Traditional Medicare enrollees who met study inclusion criteria (over 500,000 or nearly 31% of the total Medicare hospice population). However, given sample size and minimal data cleaning, the 3.1 percent in potential savings should be generalizable to the total Medicare hospice user population.
Among hospice users, we found hospice-specific costs account for about 18.7\% of last-year-of-life spending (Figure 4). The Medicare program spent an estimated 20.9 billion dollars in 2019 on Part A hospice services.\textsuperscript{17} If that is 18.7\% of total last year of life spending (as in our study population), we extrapolate that Medicare decedents who used hospice likely had a total spend around $112 billion, assuming spending patterns are similar in the unmeasured group and ignoring Medicare Advantage-specific payment concerns. \textit{Combining these estimates, NORC infers that Medicare would have spent an additional $3.5B (3.1\%) in 2019 for these decedents had they not gone to hospice.}

\textsuperscript{17}“MedPAC Report to the Congress,” March, 2021.
Detailed Methodology

This analysis of 2019 Medicare decedents (2.3 million) applies CMS Medicare administrative claims, encounters, and enrollment files to observe health care utilization and define subgroups of interest from 2016–2019 data. Demographic data including date of death was captured from the 2019 enrollment file, while program enrollment status (FFS, MA, and Part D) was tallied for each of the available 12 months of data prior to death for every beneficiary.

Hospice users were identified from the presence of at least one hospice claim within 12 months of a beneficiary’s date of death. Hospice episodes were constructed by joining all claims with no more than one day between the end of the preceding claim and start of the following. Five subgroups, representing common end of EOL disease conditions—cancer, circulatory disease, neurodegenerative disease, respiratory disease, and CKD/ESRD—were constructed using the ICD-10-CM diagnosis codes on the ultimate hospice episode for hospice users, and the last week of claims for non-hospice users. This approach effectively categorized hospice users in order to better evaluate LOS and spending. Decedents with no ICD-10-CM diagnosis code matches to the five EOL disease subgroups were assigned to the “Other” disease group.

NORC calculated Medicare total costs of care (referred to as “Medicare spending”) and utilization of services in the time leading up to death, the “lookback period,” for the 12 months prior to death. The analysis further segmented utilization and spending measures by whether services occurred concurrent to the hospice stay\(^\text{18}\) and outside of the hospice stay. The primary focus of this report is the 12-month lookback period findings, and analysis of Medicare spending limited to decedents who were continuously enrolled in traditional Medicare FFS during this period.

Direct comparison of hospice and non-hospice decedents is challenging due to an inherent selection effect. People who opt to use the hospice benefit are in some cases very different from other decedents in terms of demographics, overall health status, and cause of death. To adjust for observable differences in the study populations, NORC implemented a propensity weighting method (IPTW) so that non-hospice users were assigned weights from a logistic regression modeling Hospice Use (binary, Yes/No) as the end point. This method keeps all decedents in the sample, but uses weights to assign the likelihood of exposure to the treatment group (use of hospice, in this analysis).

Decedents’ age, sex, chronic conditions (appearing before January 1, 2019), EOL disease group indicators, and Claims-Based Frailty Index (CFI) Score were used as covariates in the propensity weighting model. As a single measure of frailty, CFI correlates strongly with dependency or needing assistance for 1 \((r=0.81)\) and 2+ ADLs \((r=0.84)\). It was a vital measure in our analysis due to a lack of functional limitation assessment data and contextual Electronic Health Record (EHR) notes on beneficiary prognosis in administrative claims, as well as the gains to model fit statistics. Propensity weights were calculated for the entire decedent population as well as for each EOL subgroup, and

\(^{18}\) Both as allowable services within the benefit and unallowable, or concurrent services, to the benefit.
ranged in value from 0 to 45. These weights were then used in calculating the average TCOC for non-hospice users in the 12-month lookback period.

NORC compared the final hospice claim-through date to decedent date of death to identify over 36,000 decedents who were discharged from hospice alive and lived seven or more days. These decedents were removed from respective hospice LOS groups and excluded from this analysis.
## Appendix

### Table A1. 12-month Lookback Period Beneficiary Counts

<table>
<thead>
<tr>
<th>Disease Group</th>
<th>No Hospice Days</th>
<th>Hospice Episode LOS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>&lt; 15 Days</td>
<td>15 – 30</td>
</tr>
<tr>
<td>All</td>
<td>457,888</td>
<td>248,217</td>
</tr>
<tr>
<td>Circulatory</td>
<td>375,511</td>
<td>217,134</td>
</tr>
<tr>
<td>Cancer</td>
<td>83,374</td>
<td>88,818</td>
</tr>
<tr>
<td>Neuro-degenerative</td>
<td>260,047</td>
<td>175,132</td>
</tr>
<tr>
<td>Respiratory</td>
<td>272,330</td>
<td>142,872</td>
</tr>
<tr>
<td>CKD/ESRD</td>
<td>142,213</td>
<td>82,965</td>
</tr>
</tbody>
</table>