A Mixed Methods Study of the Implications of Medicare Hospice Policy Changes on Patient Utilization and Provider Behaviors

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Dedication

Dedicated to the loving memory of my brother, David, who lived every day with kindness, joy, purpose, and adventure.

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Abstract of Dissertation

A Mixed-Methods Study of the Implications of Medicare Hospice Policy Changes on Patient Utilization and Provider Behaviors

Hospice is a covered Medicare benefit for beneficiaries with a six-month or shorter prognosis. In October 2014, the Improving Medicare Post-Acute Care Transformation (IMPACT) Act systemized audits of hospices with high proportions of long-stay patients (>180 days). In January 2016, Medicare introduced a two-tiered reimbursement system that reduces the daily rate after the first 60 days of a patient's stay. Both policies aimed to disincentivize provider practices favoring previously more profitable long-stay patients, such as those with Alzheimer's disease and related dementias (ADRD), whose lengthy and variable end-of-life trajectories make prognostication particularly challenging.

The goal of this dissertation was to evaluate patient utilization outcomes and provider behaviors associated with the IMPACT Act and two-tier payment system. First, I leveraged 2008-2019 Medicare claims data to examine trends in ADRD hospice patient share, as well as trends in live discharges and length-of-stay across different patient groups over time and in relation to the policies. Next, I conducted and analyzed semi-structured interviews with hospice industry leaders to understand their perspectives on the policies' implications for providers and patients, as well as the appropriateness of and alternatives to the current hospice benefit.

Overall, findings suggest that policies were associated with reductions in ADRD hospice patient share, and a relative increase in live discharges across all diagnoses, with

more pronounced effects in for-profit hospices. Hospices primarily responded to the IMPACT Act through strengthening adherence to hospice eligibility guidelines and patient eligibility documentation efforts, which were noted by interview participants to result in delayed/missed admissions and increased live discharges, particularly for hard-to-prognosticate patients. However, there was no indication from participants of any financially-motivated responses to the two-tier payment system. Notably, despite evidence of increased restrictions in access, there was no corresponding reduction in patient length-of-stay, which instead rose at faster rates after implementation of the policies. Finally, industry leaders generally considered regulations around length-of-stay to be detrimental to patient end-of-life care quality and burdensome to providers, with little effect on fraud deterrence. With a rapidly growing number of chronically-ill older adults, it is vital to investigate and consider alternative cost-effective and patient-centered approaches to end-of-life care.

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Chapter 1: Literature review, research aims, and conceptual framework

I. The Medicare hospice benefit – overview and recent changes

While modern medicine has led to vast improvements in life expectancy, it has also increased the disease burden and prolonged the dying process among the elderly (age 65 and over), who accounted for over 74% of the U.S.'s 2.9 million decedents in 2019.[1] Nine tenths of the aged population suffer from at least one chronic illness, and up to two thirds suffer from multiple chronic illnesses.[2,3] As a consequence, death among this population typically comes after a long, drawn-out process of physical and mental decline; a 2002 analysis of Medicare data found that just 7% of the elderly experience sudden deaths.[4] Faced with a rapidly increasing aging population, with those aged 65 and older making up close to 15% of the US population in 2016 (a number that is expected to increase to 22% by 2050),[5] it is important that end-of-life (EOL) care coverage under Medicare – the primary insurer for the elderly in the U.S. – is well-aligned with patient needs. At the same time, it must also be cost-effective: Medicare accounts for 15% of total federal spending, with over 25% of Medicare spending directed toward the care in the last year of life for just 5% of beneficiaries (a statistic that has held true since the end of the 1970s).[6,7] Hospice and palliative care "prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual"[8] for patients with life-threatening conditions and their families. Leveraging an inter-disciplinary team-based approach, hospice and palliative care aims to improve the quality-of-life and help patients maintain as active of a life as possible.[3,8] –It is an approach to care that is more humane – providing better

quality and outcomes (better symptom management, higher quality-of-life and care satisfaction, highest likelihood of dying at home) – while being less costly and resource-intensive than the conventional approach to EOL care.[3,9–13] It has been recognized by the IOM as the "best chance of maintaining the highest quality-of-life for the longest possible time."[3]

The U.S. hospice care movement began with a 1963 lecture on care for the dying at Yale University by Dame Cicely Saunders, who went on to found the first modern hospice in the U.K. in 1967; the first hospice in the U.S. was founded in Connecticut seven years later.[14] The first testimony before the U.S. Senate on the subject of EOL care was given by Dr. Elisabeth Kubler-Ross in 1972, and by the end of the decade, the U.S. Department of Health, Education, and Welfare (HEW) and the Health Care Financing Administration (HCFA)[a] began to recognize hospice as a potentially viable approach to care that could deliver better outcomes for patients and their families while reducing costs, and initiated a demonstration program with two dozen participating hospice programs across the country.[14] Though the cost-effectiveness of hospice was not yet grounded by rigorous evidence, its benefits had proven sufficient for Congress to authorize it as a covered Medicare benefit, and was enacted with various cost-containment mechanisms through the Tax Equity and Fiscal Responsibility Act (TEFRA) in 1982.[15,16] Hospice became accredited by the Joint Commission on Accreditation of Hospitals (JCAHO) two years later, and subsequently recognized as part of the health care continuum at the beginning of the 1990s when it became classified as a guaranteed service under President Clinton's health reform.[14] By 2019, the hospice industry had

[a] HCFA became the Centers for Medicare and Medicaid Services (CMS) in 2001.

grown to 4,840 Medicare-certified agencies, which provided services to an annual 1.6 million Medicare-insured decedents for $20.9 billion.[17]

The Medicare hospice benefit covers a broad and holistic set of biomedical, psychosocial, and spiritual services aimed to palliate symptoms and maximize comfort for terminally ill patients, and to provide support to the patient-and-family unit.[3,18] These services include physician, nursing, social worker, home health care, physical and emotional therapy, medical equipment and drugs, bereavement support, and chaplain visits.[19] Hospice services are most commonly provided in the patients' place of residence, accounting for 98% of Medicare-hospice covered days.[20,21] Patients who wish to elect it must receive a prognosis of 6 months or less (under the assumption that the disease runs its normal course) from both their referring physician and a hospice physician, though prognostication, particularly following hospice admission guidelines, can be difficult and unreliable for many patients.[19,22,23] Patients receive an initial benefit period of 90 days, after which they must become re-certified (based on the same 6-month prognosis criterion) for a second 90-day benefit period, and then re-certified every 60 days thereafter.[19] Once beneficiaries elect the Medicare hospice benefit, which is paid by Part A, Medicare ceases coverage for any services related to the terminal condition furnished by providers outside of the designated hospice agency or attending physician[b,c] (paid by

[b] The attending physician – who typically co-manages patient care with the hospice program to varying degrees – is most often designated to the primary care physician (MD) or nurse practitioner (NP) most involved with the patients' care leading up to hospice enrollment.[221,222]

[c] Currently, Federally-qualified Health Center (FQHC) and Rural Health Center (RHC) clinician services are reimbursed through an all-inclusive payment under Medicare Part A rather than as Part B physician services, and thus FHQC/RHC physicians are not eligible to serve as attending physician to their patients who wish to elect hospice.[24] This limitation poses significant barriers to those residing in rural areas and Health Professional Shortage Areas (HPSAs), who are most likely to have a primary care provider from an FQHC/RHC. The *Rural Access to Hospice Act*, first introduced in 2016 by Senators S. Capito (R-WV) and J. Shaheen (D-NH), amends the current legislation to allow FQHC/RHC to serve as attending physician for hospice patients and receive Medicare payments for providing treatments and consultation related to the terminal condition.[24] This Act is expected to improve the quality of EOL care by facilitating the continuity of care through the curative-palliative transition. Notably, based on various population projections,[223–225] the population of elderly rural dwellers whose EOL care may be impacted by this Act may reach well over 15

Part B).[24–26] This curative-palliative trade-off that the Medicare hospice benefit imposes is viewed as a key barrier to timely hospice enrollment in the U.S., as many patients have difficulty forgoing curative treatments.[3,27–29] Patients may choose to revoke hospice at any time to regain conventional and curative service coverage, or they may be discharged alive by their hospice provider if their conditions plateau or improve; patients may subsequently re-enroll in hospice at a later time provided that they meet the eligibility requirement.[30,31]

Since it was first enacted in 1983, the Medicare hospice benefit has reimbursed providers on a per-diem payment schedule, whereby the daily rate is intended to cover the costs of all services related to the palliation of symptoms and management of the hospice-qualifying terminal condition and other listed conditions that are related to or contribute to the terminal illness.[32] The hospice provider incurs the full financial risk of providing care to the patients they admit, and pocket any residuals when the daily rate exceeds the cost of care.[19] While hospices can include any service that they deem to be appropriate under the plan of care – whether palliative or curative – they must cover the cost of those services under the daily rate; thus, hospices are typically constrained in their ability to afford costly treatments. There are four levels of payment corresponding to four categories of care, adjusted for inflation over time, as well as differences in wage rates across geographical areas.[d,16,19,33] Routine home care (RHC) is the lowest-intensity level of care, provided at the patients' primary place of residence through visits from members

million by 2050. The Act was introduced in April 2016 (114th Congress) read twice and referred to the Committee on Finance, where it was subsequently killed in the Committee on Finance. It was most recently introduced in the House again in May 2019 (116th Congress), and was ultimately referred to the Subcommittee on Health.[24,226]

[d] Additionally, since 2014, when requirements to hospice to report quality data was implemented under S. 3004 of the Affordable Care Act (ACA) amended hospice, CMS began imposing a 2% penalty on reimbursement rates to non-compliant hospices.

of the hospice team; the base RHC rate grew from $63/day in 1986 to $159/day in 2015.[16,33,34] RHC payment was updated to a two-tiered system in 2016, a change that will be discussed in further detail in section VI of this chapter, and is reimbursed at a base rate of $161-203/day in fiscal year (FY) 2022 (**Table 1**).[35] Of note, primary place of residence for RHC includes skilled nursing facilities and assisted living facilities in addition to personal homes; patients who reside in skilled nursing or assisted facilities receive hospices services along with services from the living facility. Conversely, continuous home care (CHC) is an option for short-term crises that call for at least eight hours of specialized care at home, and is the only level of care that is reimbursed at an hourly rate. Inpatient care falls under two classes: general inpatient care (GIP) is provided in cases where symptoms cannot be managed outside of an inpatient setting for short periods of time, while inpatient respite care (IRC) can be provided for up to five days for the purposes of giving hospice patients' informal caregivers a break for caregiving duties.[16,35] Reimbursement rates for each of these levels of services are summarized in **Table 1**.[16,35]

Table 1. Medicare hospice reimbursement rates, 1986-2020

	FY 1986 base rate	FY 2020 base rate
Routine home care	$63/day	$161-203/day
Continuous home care	$15/hour	$61/hour
Inpatient Respite Care	$65/day	$474/day
General Inpatient Care	$281/day	$1068/day

Furthermore, consistent with Congress's cost-saving intent embedded in the decision to approve the Medicare hospice benefit, important cost-containment caps were built into the benefit design.[16,19,36] First, they imposed a cap on the aggregate number of service days that hospices are able to bill Medicare at inpatient care rates, beyond which any additional days of inpatient care provided would be reimbursed at the RHC rate

(leaving the hospice to make up the difference); this cap has remained at 20% of total patient days of service since the implementation of Medicare hospice benefit and is rarely exceeded.[16,19] As a consequence of this cap, hospice care in the US is primarily a home-based service, with the overwhelming majority of Medicare-covered hospice days being provided at the RHC level: in 2016, RHC made up 98% of Medicare-covered hospice days, while CHC, GIP, and IPC respectively accounted for just 0.3%, 1.5%, and 0.3% of days.[20] Second, they imposed a cap on the average annual per patient payments that can be billed to Medicare; this cap began at $6,500 in FY 1983, and has been adjusted up to $31,298 by FY 2022 to account for annual inflation.[16,35] Hospices are required to complete an aggregate cap determination within three months after the end of the cap year (Oct 1. – Sep. 30 beginning in FY 2018), and return any payments in excess of the cap (calculated as the annual per patient cap amount multiplied by the number of patients admitted during the cap year) to the Medicare program; Medicare ceases making any further payments to hospices who fail to meet this requirement.[9,33] Notably, because the payment cap calculation is based on per patient averages, hospices are able to have long-stay patients as long as they are balanced out with sufficient shorter stay patients to maintain a below-cap average. The number of hospices that exceed the aggregate payment cap has risen from under 3% at the turn of the millennium to over 12% in recent years.[19]

Until recently, the design and implementation of the Medicare hospice benefit has remained largely unchanged since its enactment in 1983. One notable innovation project was implemented on January 1, 2016 in effort to facilitate more timely access to hospice services and reduce risk of late hospice enrollments, which are detrimental to the quality

of EOL care of patients and their families.[19] Specifically, the Center for Medicare and Medicaid Innovation (CMMI) began piloting a concurrent-care model whereby terminal patients with a 6-month or less prognosis may elect to receive "hospice-like support services" from hospices participating in the demonstration, while continuing to receive Medicare-covered curative services for the terminal condition from other providers.[19,37] Previously tested by a private insurance plan, concurrent models have been shown to reduce barriers to hospice election and increase rate of hospice utilization, as well as care quality and satisfaction among terminally ill patients.[3,37,38] Known as the Medicare Care Choices Model, this demonstration was authorized under S. 3201 of the ACA and reimburses participating hospices on a capitated basis, at $200-$400/month, to provide palliative services for each patient electing this option, and had 82 participating hospices across the country as of January 2022 (down from the 141 hospices originally invited to participate in the demonstration).[37,39]

Conversely, two other recently implemented policies, which are evaluated in this dissertation, likely increased barriers to timely hospice access for many patients. In October 2014, President Obama signed the Improving Medicare Post-Acute Care Transformation (IMPACT) Act into law. This act primarily focuses on standardizing reporting on quality-related measures across post-acute care settings including skilled nursing facilities, home health agencies, long-term care hospitals, and rehabilitation facilities.[40,41] Specific to hospices, however, the IMPACT Act imposes more stringent regulatory oversight by (1) increasing the requirement for hospices to complete

recertification surveys every three years from every six years,[e] and (2) requiring medical reviews (i.e. audits) of the care provided to patients with long stays (>180 days) at hospices for which the total proportion of such patients exceeds a threshold specified by the Department of Health and Human Services (HHS).[40,41] The latter clause is most concerning for timely access to hospice, as providers may defer or even avoid certifying eligibility for certain patients to mitigate the risk of patient stays exceeding six months.

Secondly, under S.3132(a) of the Affordable Care Act (ACA), the RHC payment schedule was updated on January 1, 2016 to a two-tiered payment system with a service intensity add-on (SIA).[42] This was a response to long-standing concerns around the misalignment between the previously used flat per-diem payment scheme and the actual costs of providing hospice care, which are highest during the first and last weeks of a patient's hospice episode. This misalignment had created incentives for hospices to select for longer-stay (and lower care-intensity) patients to maximize profit.[17,42–44] Under the new system, the base reimbursement rate for FY2022 is $203/day for the first 60 RHC days of a hospice episode, and drops to $161/day starting on day 61;[35] as with previously, these rates are adjusted by the hospice wage index to account for wage differences across geographical areas.[33,35] Under the SIA, direct patient care that is provided by a registered nurse (RN) or social worker during the last seven days of life of an RHC episode is additionally reimbursed by the hour at the CHC rate (base rate of $61/hour in 2022).[45] Coupled with the IMPACT Act, this direct reversal of the monetary incentive structure of the RHC payment schedule aims to further discourage hospice agencies from favoring

[e] Hospices that receive Medicare funds must undergo re-certification surveys to ensure that they remain compliant. A 2013 OIG reported that an assessment of hospice agency compliance found 14% of hospices to be non-compliant with the 6-year recertification clause, and that among sampled agencies who *did* file a recertification survey, almost half received notices for "care deficiencies."[227]

long-stay patients and admitting patients "too early" in the course of a terminal illness. Notably, both policies rest on the assumption that end-of-life prognostication accuracy is consistently high. In practice, there is a high degree of uncertainty around end-of-life trajectories, and six-month prognostication is difficult for many patients, including those with advanced dementia, heart disease, and lung disease.[22,23]

II. Hospice Care Outcomes

Studies suggest that hospice and palliative medicine improves the quality-of-life, and in some instances even increases the length of life.[3,10,27,46] Despite the fact that most studies of hospice care outcomes are considered to have lower validity (due to the ethical challenges of conducting large, randomized controlled trials),[12,47–49] the European World Health Organization (WHO) Regional Office declared the goal of improving elderly access to hospice and palliative to be a public health priority in a 2004 report, noting that the elderly were suffering unnecessarily due to inadequate hospice and palliative care utilization.[50] It is challenging to assess hospice care outcomes because hospice patients ultimately die, not only rendering survival (a commonly used measure to assess health intervention outcomes) inadequate, but also eliminating the possibility of collecting post-intervention self-reported outcomes from patients themselves. However, as discussed below, the current evidence around hospice outcomes (using a variety of methods and outcome measures) does suggest that for most, the hospice approach is preferable to the traditional approach to care for patients nearing EOL.

First, despite the fact hospice care is not intended to prolong life, limited evidence from quasi-experimental methods suggest that certain cancer patients enrolled in hospice live longer than matched non-hospice enrolled counterparts.[3,51–54] This may be a result of

greater comfort, improved psychological and emotional health, better monitoring and management of symptoms, stronger social support, and reduced risks and side-effects associated with conventional aggressive treatments.[27,53] Another commonly cited measure of good EOL outcomes is place of death. Surveys conducted both in the U.S. and internationally show that the large majority of people (up to 90%) prefer to die at home.[3,55,56] Studies find that enrollment in hospice care, which is typically provided in the home setting, is strongly associated with dying at home. An analysis of 2007/2008 Medicare-covered cancer decedents found that 70% of hospice enrollees died at home while another 13% died in a nursing home, with just 6% dying in a hospital setting.[12,57] In comparison, across all 2009 Medicare decedents, only 34% died at home while 28% died in a nursing home, with 35% dying in a hospital setting.[58] A meta-analysis of literature published through 2012 further concluded that the odds ratio of dying at home for hospice-enrolled patients is 2.2 (CI: 1.3-3.7) compared to non-hospice enrolled counterparts.[12] Similarly, research suggests that the receipt of CHC reduces the odds of hospitalization and increases the odds of having a home death.[59,60] It is important to note, however, that these studies do not demonstrate causality: while it is possible that hospice care can increase the chances of dying at home, it is also possible that individuals who elect into hospice are also those who would have resisted hospitalization prior to death regardless of hospice.

Overall quality-of-life and satisfaction with care has been rated more highly among patients (as well as their family members) who received hospice or specialized palliative care at the EOL, compared to patients who received conventional care.[13,48,61–66] In a 1999 cross-sectional survey of seriously ill patients, family members of recently

deceased patients selected randomly from the Veterans Affairs (VA) patient database, and of professional EOL caregivers selected randomly from professional associations, authors identified various factors that were consistently rated as being important in EOL care across all three participant groups.[67,68] Many of these factors– including symptom management and comfort, emotional health, feeling prepared to die, as well as maintaining dignity and "being treated as a whole person" – are better served by the hospice approach to care, which aims precisely to provide holistic care in accordance with patient values and preferences.[3,27,67,68] Despite inconclusive findings from many studies conducted to compare these outcomes between hospice and conventional care, there is some quantitative and qualitative evidence demonstrating that hospice-enrolled patients and patients receiving home-based palliative care experience better outcomes in these various domains.[12,47,48,69] For example, a comparison of nursing home-dwelling cancer patients found that those enrolled in hospice received better pain management than matched patients not enrolled in hospice.[70] A recent study of Veterans Affairs (VA) patients with end stage renal disease similarly found that quality of EOL care was more likely to be rated as excellent by family members of those who received hospice services.[69] In another study, pre- and post-hospice admission surveys of community-dwelling older adults found hospice admission to be associated with significant declines in symptoms that restrict daily activities.[71] Hospice care has also been found to improve emotional health and reduce depressive or anxiety symptoms among cancer[51,61] and other terminally-ill patients.[63,71] While there is no research directly examining the effect of hospice enrollment on patient feelings of dignity, respect, or being treated as a 'whole person,' there are studies demonstrating that palliative care consultations and improved

patient-physician communication are positively associated with these outcomes; furthermore, because the hospice care philosophy is one that inherently prioritizes patient dignity, goals and values, it is unlikely that hospice would perform worse than conventional, institutionalized care in this domain.[3,27,72] Finally, because the hospice approach to care treats family members as part of the patient unit, providing them with emotional, spiritual, bereavement, and social support services that continue post-death, hospice care has also been found to benefit family caregiver well-being and satisfaction by reducing their emotional and caregiving burdens, as well as easing their grieving process.[3,18,48,73–75]

Central to this dissertation, a key factor that influences the effectiveness of hospice on patient outcomes is patient length-of-stay (LOS). This is because very short hospice stays do not allow providers the opportunity to provide the full spectrum of care necessary to maximize comfort, thus limiting patients' ability to enjoy the full extent of quality-of-life benefits that the hospice benefit offers; additionally, because short hospice stays tend to come after the full (or close to the full) course of conventional, aggressive care has already been exhausted, hospice simply constitutes an added and burdensome care transition immediately prior to death.[3,10,76–78] Studies have consistently shown that patient/family perceptions of hospice referrals that are too late and hospice stays that are too short are associated with lower satisfaction and lower quality of care in the form of fewer services provided, higher unmet needs, worse care coordination, and lower likelihood of dying at home.[76,77,79–86]Additionally, very short hospice stays have been found to be associated with increased family caregiver risk of developing major

depressive disorder (in one study, for example, OR = 8.67, CI: 1.09 – 70.19), though this conclusion is not consistent across studies.[81,87]

Longer hospice LOS is especially beneficial to non-cancer patients who have lengthy and unpredictable EOL trajectories, including patients with terminal Alzheimer's disease and related dementias (ADRD), for whom early access to such services can substantially increase the quality-of-life for both patients and their family caregivers.[88–96] Notably, from both a clinical and a family caregiving perspective, the EOL period for ADRD patients during which they may benefit from hospice begins years before death, far before the 6-month Medicare eligibility threshold.[89,91,97] This is because late-stage ADRD patients experience a complex combination of physical symptoms (e.g. pain, dyspnea, choking/coughing), psychological symptoms (e.g. depression, confusion, agitation, behavioral changes), limitations to basic activities of daily living (ADLs), and a high risk of infections over an extended period of slow decline.[3,98–100] In these circumstances, an aggressive approach to care tends to impose greater quality-of-life burdens and discomfort to patients for minimal (if any) life-prolonging benefits; conversely, early integration of hospice care is better able to meet patients' multi-faceted needs, and is more likely to provide high quality-of-care and quality-of-life.[3,64,80,90,98,101–104] Furthermore, the prolonged symptoms of ADRD – including changes in behavior and character, the loss of communication skills, and the decline in ability to perform basic functions – pose uniquely burdensome demands on family caregivers, who in turn report high rates of physical, emotional, psychological, and financial stress.[90,91,98] Evidence across studies of ADRD family caregivers highlight the importance of having ongoing psychological, practical, and educational support from health professional for family

caregivers' wellbeing; by following a holistic patient- and family-centered approach to care, hospice is particularly beneficial to the well-being of family caregivers of ADRD patients.[3,91,98,105]

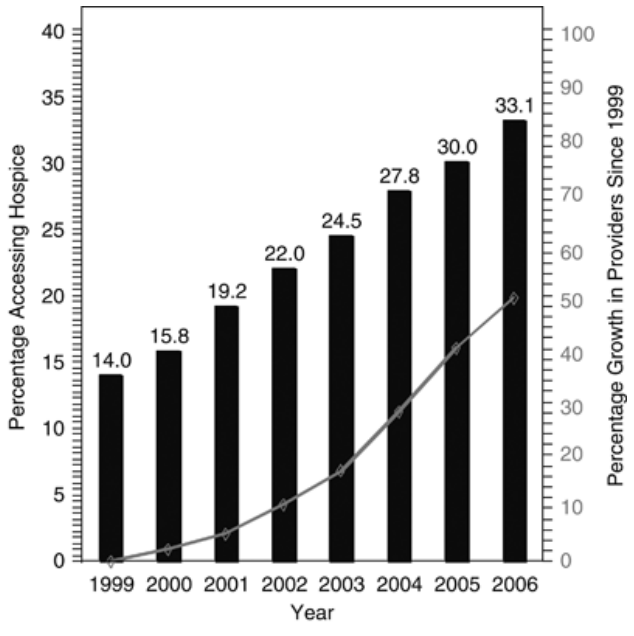
A key mechanism through which hospice care improves quality-of-life relative to conventional care is the reduction of aggressive procedures, which typically carry burdensome side-effects that outweigh benefits for patients who are nearing the EOL.[3,10,27,83,106,107] Because these types of interventions also tend to be very expensive, a hospice approach to care is also a more cost-effective approach to EOL care relative to the standard, aggressive approach to care.[3,10,27,46,108] Researchers have found, for example, that hospice enrollment reduces costly hospital visits, ICU days, rehospitalization rates, and intensive/aggressive procedures.[50,65,106,107,109,110] Notably, overall savings may be higher with longer hospice stays than with very short stays which, as mentioned previously, essentially constitute an added cost after an extensive course of costly and aggressive interventions have already been provided and paid for.[30] For example, Taylor et al.'s 2007 cost-effectiveness study, which compared matched hospice and non-hospice Medicare deaths using a decade's worth of National Long Term Care Survey data (1993-2003), found that the maximum savings were accrued from hospice stays lasting from 50 to just over 100 days prior to death, and that 70% of Medicare users were not transitioning into hospice sufficiently early.[109] Overall, the evidence in the existing literature is consistent in demonstrating that hospice care is more cost-effective compared to conventional care, though there still remains substantial uncertainty around the extent to which it is more cost-effective, and how cost-effectiveness may vary by factors such as patient type and LOS.[48,110–112]

III. Trends in hospice utilization

a. Patient demographic trends

Hospice use has grown steadily since it first became a covered Medicare benefit, from serving just 25,000 patients annually in the early 1980's, to 540,000 by 2000, to well over 1.6 million patients in recent years.[19,58,113,114] The proportion of hospice enrollees with Medicare as their primary insurance has increased substantially, from 63% in the early 1990's to 79% by 2000, to over 90% in recent years.[20,115,116] Among Medicare beneficiaries, the percentage of decedents enrolled in hospice exceed half (at 50.4%) for the first time in 2017, up from just 23% in 2000.[117,118] While hospice enrollment rates for Medicare Advantage (MA) beneficiaries were about ten percentage points higher than enrollment rates for fee-for-service (FFS) beneficiaries in 2000, that gap had shrunk to just over two percentage points by 2019 (53% versus 51%).[113,119] Hospice use has grown faster among women (from 23% of decedents in 2000 to 56% in 2019) compared to men (from 22% of decedents in 2000

Figure 1. Percentage of nursing home residents with hospice use and growth in hospice providers caring for nursing patients, 1999-2006



Source: Miller et al. 2010. JAGS

to 47% in 2019).[113,119] Growth has also been fastest among those aged over 85, tripling from 21% to 63% of decedents between 2000 and 2019; in comparison, hospice use among Medicare-covered decedents aged 65-84 has grown from 25% to 47% over the same time period.[113,119] Notably, though only 1% of nursing home residents elected hospice in the early 1990s,[120] this figure that has grown considerably in subsequent years (**Figure 1**).[121] This trend is paralleled by the proportion of hospice providers that provided care for any nursing home patients (**Figure 1**[121]), which will be discussed in further detail in **Section V**.

As with most other health care services, racial/ethnic disparities also exist in hospice utilization rates, and have become wider in recent years, from a seven percentage point gap in utilization rate between white decedents and minority decedents in 2000 (24% versus 17%) to a 13 percentage point gap by 2019 (54% versus 41%).[113,119] Various barriers to adequate hospice utilization among EOL African Americans and Hispanics have been proposed, including inadequate communication with physicians about EOL preferences, lack of resources and caregiver support at the EOL,[f] spiritual and cultural beliefs that conflict with the hospice approach to care, differences in health literacy level, as well as lower rates of participation in advance directives or advance care planning (oftentimes due to a lack of knowledge and/or negative perceptions about the withdrawal of aggressive care).[3,122,123] Furthermore, due to the historical exploitation of and discrimination against African Americans in health care, many African Americans have a strong sense of distrust of the medical system, oftentimes driving them toward more

[f] Because the majority of hospice care is provided at home in the U.S., a high-quality and successful hospice experience is highly dependent on the availability of family caregivers and home resources.

intensive, but typically ineffective treatments intended to sustain life at the EOL.[3,123,124] For Hispanics, language difficulties and a lower understanding of the health care system have also been cited as barriers to adequate hospice utilization.[122]

b. Trends in hospice patient diagnoses

The Medicare hospice patient diagnosis mix has also changed substantially over this time period. When the Medicare hospice benefit was first enacted, hospice users comprised almost exclusively cancer patients, for whom the six-month eligibility criteria was fitting due to their predictable and relatively short EOL trajectories.[3,27,44,92,125,126] Since then, however, the hospice patient mix has become increasingly diverse: the portion of cancer patients steadily decreased to just 25% by 2019 (**Table 2**).[118,119,127] Among the fastest growing hospice patient types over the past decades has been those diagnosed with ADRD or other nervous system disorders, making up just 1% of total enrollees in the early 1990s, compared to 24% (coming in just after cancer patients) by 2019 (**Table 2**).[118,119,127] The next largest hospice patient groups in recent years are those with terminal circulatory and heart disorders, as well as respiratory and airway disorders, which collectively made up fewer than 20% of hospice enrollees in 2000 (**Table 2**).[118,119,128]

Table 2. Change in hospice patient diagnostic mix from the early 1980s to 2019[118,119,127,128]

	Early 1980s	**Early 1990s**	**Late1990s / Early 2000s**	**2019**
Cancer	100%	76%	63%	25%
ADRD	0%	0.3-1%	3%	24%
Circulatory disorders (except heart failure)	0%	6%	11%	21%
Heart Failure	0%			9%
Respiratory disorders	0%	3%	4%	6%

c. Hospice length-of-stay (LOS) trends

Mean hospice LOS declined before the turn of the millennium, from 75 days in 1992 to around 50 days in the early 2000s,[g] before rising again to 93 days by 2019.[118,119,128,129] Conversely, the median hospice LOS increased in the 1990s (from around 26 to 48 days over the course of the decade), and then shortened to 17 days by 2000, where it has held largely steady until 2019 at 18 days.[118,119,128,129] These trends can be attributed to the changes that have occurred at the tail ends of the LOS distribution over the years. The portion of short-stay patients (0-7 days) increased by over 14 percentage points from 1991 (23%) to 2000 (37%) while the proportion of long-stay patients (> 180 days) dropped by just over four percentage points over the same period, from 9% to 5%.[g,127] The rise in average hospice LOS since the early 2000s can be explained by substantial increases in the portion of long-stay patients (20% by 2017), with the 90th percentile LOS rising from 141 to 266 days between 2000 and 2019.[118,119] Conversely, the proportion short-stay patients has remained largely constant, with approximately one quarter of patients being referred to hospice fewer than 6 days prior to death.[118,119] Despite making up just one fifth of total Medicare enrollees, hospice care for long-stay patients (>180 days) accounted for almost two thirds of total Medicare hospice payments ($10.1 billion out of $17.9 billion) in 2017.[118] Though this is cited as a source of concern from a cost perspective, it is important to remember that hospice costs largely substitute for conventional care costs and only exceed expected care costs under conventional care in very long stays.[30,109] Furthermore, because cost savings accrued

[g] It is speculated that the downward LOS trend in the 1990's occurred partially as a result of President Clinton's Operation Restore Trust (ORT) initiative in 1995, which comprised audits of hospices with large numbers of long-stay patients.[36] This will be discussed in greater detail under Section V.

from shortening very long stays may also be achieved by lengthening short stays, efforts should be directed at avoiding very short stays rather than very long stays if the goal is to maximize EOL quality-of-care and quality-of-life.[109]

The rise in the percentage of long-stay patients can be largely attributed to the substantial changes in hospice patient-mix over the past two decades. As cited previously, there has been a shift away from cancer patients toward patients with terminal ADRD and patients with circulatory and respiratory disorders. Advances in modern medicine have reduced cancer death rates by over 20 percentage points over the past two decades,[130] while at the same time delaying and prolonging the process of dying from other terminal conditions; this process often involves the management of multiple comorbidities, increasing frailty, and general functional and mental decline.[3,27] Unlike terminal cancer patients, who experience a short and predictable period of decline at the EOL, patients diagnosed with other terminal illnesses – especially those with a primary ADRD diagnosis – have significantly longer, less stable, and less predictable EOL trajectories, which increases the level of uncertainty and difficulty of ascertaining a 6-month prognosis for physicians.[27] In 2015, only 9% of patients with a primary cancer diagnosis had a hospice LOS exceeding 180 days, compared to 34% of patients with a primary diagnosis of ADRD or other neurological disorders, 27% of patients with a primary diagnosis of chronic obstructive pulmonary disease (COPD), and 25% those with a primary diagnosis of circulatory disorders.[118,131] Similarly, the mean (median) LOS was 53 (18) days among cancer patients, compared to 147 (33) days, 91 (15) days, and 116 (24) days respectfully for patients with terminal neurological disorders, circulatory disorders, and COPD.[118]

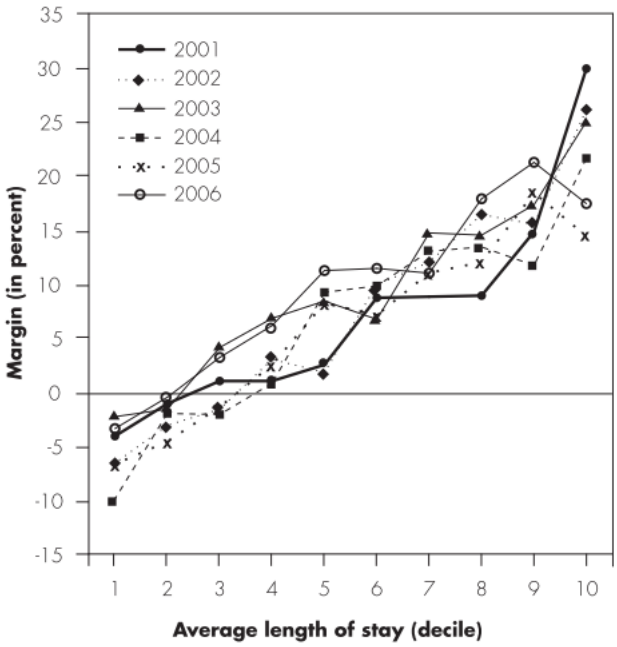
IV. Hospice industry trends and practices

In the early days of hospice care, providers were sparse and consisted exclusively of charitable and non-profit institutions.[46] The U.S. hospice landscape has shifted considerably since then, with the number of hospices exceeding 1,500 after it became a covered Medicare benefit in 1983, and reaching almost 5,000 by 2013.[132] With respect to Medicare-certified hospices, the number has grown from just over 2,000 at the turn of the millennium, to close to 5,000 by 2019.[17,96] Notably, growth has been largely driven by the expansion of the for-profit hospice industry; specifically, the number of Medicare-certified for-profit agencies increased from under 700 to 3,437 between 2000 and 2019, while the number of non-profit/government agencies has remained steady over this period.[113,133] Along with the growth in hospice agencies and patient enrollments, Medicare hospice outlays have risen at a staggering rate, from less than $100 million annually in the 1980s, to over $2 billion by the end of the 1990s and almost $21 billion by 2019.[17,36]

There is strong evidence that for-profit hospice operations and practices are more profit-driven than those of non-profits, exhibiting preferential admission practices for non-cancer patients who have longer and less predictable EOL disease trajectories, and who also typically require fewer skilled visits; in particular, studies have highlighted that ADRD patients (whose unpredictable EOL periods of decline can last up to two years) were admitted at approximately double the rate to for-profit compared to non-profit agencies.[44,89,92–95,133,134] In 2015, for example, the mean LOS at for-profit hospices was 105 days, compared to 65 days at non-profit hospices; the median/90th percentile LOS

was 21/304 days at for-profits and 13/176 days at non-profits.[113] Long-stay patients were more profitable than short-stay patients under the flat reimbursement system because the care provided during the first and last days of a hospice stay are typically most costly to the agency. In its 2009 Report to Congress, the Medicare Payment Advisory Committee (MedPAC) demonstrated that hospice agency profit margins grow almost linearly with the average LOS of their patient population, with hospices ranked in the lowest two deciles of average patient LOS experiencing slightly negative margins (**Figure 2**).[43] In a subsequent Report to Congress, MedPAC analyzed 2008-2009 patient-level data to find that the average labor cost of providing care (across all diagnoses and hospices) to be $86 on the first day of a hospice stay, declining to $15 by day 30 of a stay, and then rising to $30 approximately one week prior to death, before reaching $64 on the day of death.[30] Some evidence also suggests that for-profit hospices provide fewer services than their non-profit counterparts.[93,135,136] Consequently, Medicare margins at for-profits have remained between 10 – 19% over the past 15 years, compared to margins at non-profits, which have hovered between -0.7 –

Figure 2. Association between hospice profitability and average length of stay



Source: MedPAC Report to Congress 2009

3.6%.[113,119,137] By the same token, the proportion of hospices exceeding the Medicare cap has been consistently higher among for-profits (in 2005, close to 9% of for-profit hospices exceeded the Medicare annual cap, compared to just 0.7% of non-profit hospices, and 0.1% of government-owned hospices).[138]

There is also evidence to suggest that for-profits may be admitting relatively healthier patients who are earlier in the disease trajectory. First, the difference in overall LOS cannot be accounted purely by differences in patient diagnostic mix, as hospices with a higher proportion of non-cancer long-stay patients have longer average LOS across all diagnoses compared to hospices with fewer non-cancer patients.[43] Second, because the Medicare hospice benefit is intended to care for terminally-ill patients through death, high rates of live discharges can indicate either poor quality care (i.e. the hospice is not meeting patient/family needs), or that non-terminally ill patients are being inappropriately admitted.[139] For-profit hospices and hospices with longer LOS/higher profit margins have higher rates of patients who are discharged alive, who tend to be healthier at the time of admission, require less care, and on average live longer than patients who die in hospice.[44,140] For example, the rate of live discharge was 22.4% among for-profits vs. 14.6% among non-profits in 2010, and analysis using 2011-2013 data found a one-unit increase in total margins to be associated with 4% increase in live discharge rates, controlling for various patient- and hospice-level characteristics.[139,141,142] Because hospices were paid on a flat per-diem rate, it is unlikely that the higher rate in live discharges at more profitable hospices can be explained by a reversal in disease trajectory resulting from higher-quality care. Among all live discharges, under two fifths result from patient/family revocation of the benefit, while another two fifths result from a

"no longer terminally ill" determination by the hospice provider.[113] Those deemed no longer terminally ill include patients who experience a reversal in EOL trajectory, as well as patients who may not have been terminally ill when admitted; however, because it has been found that some provider-invoked live discharges are motivated by fear of exceeding the Medicare cap and/or concerns about being audited for having long patient LOS, such discharges may be potentially compromising patient care.[31] However, despite consequences to patient care, hospices currently face no disincentives to initiating live discharges due to the lack of penalties – financial, regulatory, or otherwise – associated with this practice.

Finally, as a consequence of nursing homes being considered as patient homes for the purposes of RHC reimbursement, hospice industry trends in the care of nursing home residents have raised similar concerns regarding potentially profit-driven admission practices since the late 1990s.[120,143–147] Nursing home residents are relatively more profitable for two reasons. First, hospices are reimbursed at the same RHC rate for providing care to nursing home patients as they are for providing care to community-dwelling patients, even though provision of care to nursing home patients is less costly due to both clustering of patients in a centralized location (thus reducing the amount of time and resources that hospice staff need to spend traveling between patients), and the provision of skilled nursing care services by nursing home staff, which accordingly reduces the extent of patient care responsibilities that are borne by hospice staff.[146,147] Second, nursing home residents tend to have longer hospice stays (which, as discussed previously, were more profitable under the previous RHC reimbursing system) given that the diagnostic mix is disproportionately represented by conditions such as ADRD with

longer trajectories.[143,145,148] Nearly all hospices have provided care to Medicare beneficiaries residing in nursing homes in the past decade, but the distribution of care of nursing home residents is not equal across hospices, with for-profit agencies being disproportionately likely to have a high percentage (as much as two thirds or higher) of nursing home patients.[145] Furthermore, the percent of hospices with common ownership with a nursing home have grown rapidly: from under 15% in 2005 to approximately 40% by 2015 among chain establishments, and from 2% to 5% over the same time period among non-chain establishments,[149] exacerbating concerns over contractual relationships between nursing homes and hospice agencies and practices favoring nursing home patients across nursing homes.[144,146,149] Analysis of 2015 data found that Medicare margins at hospices with the highest quartile of patients residing in nursing homes averaged 16%, compared to average margins of just 2% at hospices with the lowest quartile of nursing-home dwelling patients.[147]

V. Hospice fraud, recent policy developments, and gaps in the literature

As outlined in the above sections, the previously-used flat per-diem RHC payment structure created strong monetary incentives for hospices to enroll more 'profitable' patients (i.e. patients with longer expected LOS, and especially those with a non-cancer diagnosis). The subjectivity and the increasing difficulty of applying the 6-month prognosis eligibility criterion further facilitated hospices' ability to employ profit-maximizing admission practices, as evidenced by the differences in patient profiles between for-profit and non-profit hospices described above. Along with the rise of the for-profit hospice industry, these factors raised concerns around hospice fraud in the form

of patient selection, which first began surfacing in the 1990s when audits of Puerto Rico hospices revealed that 70% of hospice patients did not meet the definition of terminally ill.[125,133] Responding to the concerns around hospice fraud, heightened hospice audits were implemented under Operation Restore Trust (ORT), President Clinton's 1995 initiative to reduce waste and fraud by home health care facilities, skilled nursing facilities, and durable medical equipment suppliers.[36,150] Over the course of ORT's two-year implementation, auditors from the Office of Inspector General (OIG) assessed numerous hospice facilities and imposed harsh penalties on questionable eligibility practices, unaccounted claims, and inappropriate kickbacks between nursing homes and hospices; over $80 million was recovered from offending hospices, and over two dozen agencies were decertified.[36] However, these audits, which relied on long patient LOS as a key indicator for dishonest practice, were believed to also create a 'chilling effect' on the practices of other hospices, as anecdotal evidence of later and fewer patient referrals (i.e. increasing patient access barriers) emerged.[36,95,151,152] Though there have not been any studies conducted to systematically examine the extent to which the chilling effect created by audits at select hospices affects hospice utilization across the board, qualitative interviews with hospice providers have cited regulatory scrutiny over Medicare hospice practices to be a key factor contributing to later referrals, shorter hospices stays, more live discharges, and poorer care outcomes over the years.[31,36,95] Furthermore, a GAO report found a correlational 20% decrease in average hospice LOS between 1992 (pre-ORT) and 1998 (post-ORT), with effects being greater among non-cancer patients.[36,125,153] However, because hospice LOS was already trending downwards in the years leading up to the implementation of ORT, it is unclear how much of the observed

20% decline is a result of the audits' chilling effects versus a continuation of prior trends.[36,153] Despite the fact that the ORT itself only lasted two years, and despite efforts on the part of the GAO and the HCFA to ease provider concerns about adequate and timely hospice access, similar hospice audits have continued over the years, and a handful of hospices faced multi-million dollar penalties in the early 2000s; most significant is the three-year audit of San Diego Hospice – one of the nation's oldest and most respected hospices – which ultimately led to its bankruptcy in 2013.[36,125,154,155]

The Improving Medicare Post-Acute Care Transformation (IMPACT) Act – passed in October 2014 – signifies an effort to systemize the hospice auditing process.[41] Similar to the ORT audits, the IMPACT Act audits are informed crucially by the proportion of agencies' patients with LOS exceeding 6-months. This is problematic not only for the reasons stated above – in that EOL trajectories are lengthy and unpredictable for many of those who benefit from hospice and palliative services today – but also for the fact that long stays are a complex signal. They are also indicators of high-quality hospice care, particularly with today's patient case-mix, as patients have been found to improve both psychologically and physically after receiving hospice and palliative services, and may consequently outlive their prognosis.[3,11,27,51,53] As such, regulatory and monetary pressures to discharge these patients are expected to negatively impact patient outcomes, as live discharges have been shown to disrupt care continuity and patient-provider relationships, result in increased rates of hospitalizations and emergency room visits, and reduce QOL for patients and families.[31,139,142,156–160]

Following the recommendations of the Medicare Payment Advisory Commission (MedPAC) from almost one decade ago, S.3132(a) under "Part III – Improving Payment

Accuracy" of the ACA tasked the HHS Secretary with collecting additional data to inform a budget-neutral update to the hospice payment system to better align it with the costs of providing care.[30,42,43,161] Their analyses confirmed MedPAC's earlier analyses showing that the misalignment between payment rates and costs of care in the early and last days of a hospice stay created incentives to providers to maximize the portion of patients with longer projected stays.[42] Additionally, recent analyses of hospice claims performed by CMS found that some hospices failed to provide any skilled home visits to over half of patients during their last two days of life, which is an indirect, but important measure of care quality because patient needs typically rise in the days leading up to death.[42,162] A similar analysis of 2005-2010 claims conducted by non-CMS affiliated researchers similarly concluded that under 45% of hospice patients received a skilled home visit from a registered nurse (RN) or social worker during their last week of life.[162] Informed by these findings, the two-tiered payment system with a service intensity add-on (SIA) took effect on January 1, 2016, which aims to better align hospice payments with costs and offset some of the profit-seeking practices that evolved with the flat per-diem system.[42,162] As discussed previously, under this system, the first 60 days of routine home hospice care is reimbursed at the higher rate, and days 61+ are reimbursed at a lower rate, with an SIA payment available for services furnished by a registered nurse or social worker during the last seven days of life.[42] A simulation of 2011 admission patterns under the new two-tiered payment rates shows that average payments to for-profit hospices would decrease by 1.5%, but increase by 0.5% for non-profits.[163] This suggests that though the new payment system is not associated with the same chilling effects that are hypothesized to accompany government audits, it may have created

financial incentives for hospices to develop practices that reduce access for patients with longer and more unpredictable EOL trajectories, ultimately creating negative, unintended consequences on patient care.[163]

Because the Medicare hospice benefit was designed to allow terminally-ill patients the opportunity to prioritize comfort and quality-of-life over prolonging the length of life, policies aimed at regulating patient LOS are a judicious response to profit-motivated admissions of patients who may not yet be at their EOL. However, as the current literature suggests, there has been a significant shift in the hospice patient profile toward greater proportions of non-cancer patients that experience long and unpredictable EOL trajectories. The IMPACT Act was passed despite longstanding concerns of chilling effects of government audits that have not been addressed or rigorously examined through research; while the potential effects of the new payment system – with no prior precedent in the context of hospice care – are even less understood. Furthermore, these reforms do not address the issue posed by the feasibility of applying the 6-month eligibility standard to today's elderly patient population, from which much of the concerns over inappropriate hospice behavior stems from; many experts have in fact called for a reconsideration of Medicare hospice eligibility to move away from prognosis-based criteria and toward severity/disability-based criteria or general efforts to better integrate hospice or palliative medicine into the care continuum.[89,92,95,152,164–166]

There is currently a stark gap in the literature to inform what the consequences of the IMPACT Act and two-tier payment system are on patient access to hospice care and EOL outcomes; with the exception of the 2000 GAO report, no efforts have been made to rigorously estimate the size of audit chilling effects, either overall or by patient diagnostic

types. The two policy changes are particularly concerning for patients with longer LOS. Notably, patients with ADRD who, as discussed previously, experience significant deterioration in health and functioning for many months, or even years, before they meet the Medicare hospice 6-month eligibility threshold, and benefit from longer hospice LOS,[23,89,92,165,166] are expected to make up over 45% of aged decedents by 2050.[167] It is therefore crucial to begin examining whether, and the extent to which these policies have affected hospice utilization for Medicare decedents overall, and among patients with ADRD. These evaluations will in turn inform future investigation on the policy effects on EOL quality-of-care and quality-of-life outcomes, and ultimately inform future efforts to advance care for the terminally-ill Medicare population, particularly those with longer and more variable EOL trajectories

VI. Research aims and conceptual framework

a. Research aims

Evaluation of the effects of the IMPACT Act and the new two-tier payment system on hospice utilization is an important first step for better understanding whether and how changes in policies and health system factors influence hospice provider behavior. Because high quality-of-life for terminally-ill patients hinges on timely access to high-quality hospice services, this understanding may inform how the Medicare hospice benefit can be improved to maximize quality-of-life for current and future Medicare populations, comprising increasingly higher proportions of patients with ADRD and other conditions that exhibit long and variable EOL trajectories. The specific aims of this dissertation were as follows:

Aim 1: To examine trends in the proportion of hospice patients with ADRD, over time and in relation to the 2014 IMPACT Act and 2016 two-tier payment, overall and within for-profit versus non-profit hospices.

Aim 2: To examine trends in hospice live discharge rates and length-of-stay over time and in relation to the 2014 IMPACT Act and 2016 two-tier payment, overall and within for-profit versus non-profit hospices.

Aim 3: To understand the mechanisms and patient implications of providers' response to the 2014 IMPACT Act and 2016 two-tier payment, as well as appropriateness of and alternatives to current Medicare hospice policies from the perspectives of hospice industry leaders.

b. Conceptual framework

To inform both the quantitative analysis and the interview guide for the qualitative component of this work, it is useful to illustrate the role of policy within a larger conceptual framework of hospice utilization. This framework formalizes the research findings on the policy-, organizational-/institutional-, and personal-level factors barriers to hospice care,[152,168–173] and is an adaptation of Andersen's frameworks of health access and utilization,[174,175] as well as Bradley et al.'s and Yabroff et al.'s subsequent modifications to the framework for illustrating long-term care (LTC) and EOL care utilization.[176,177]

Aiming to present a theoretical framework that better facilitates policy research, Aday & Andersen's model integrates various notions of access used in the literature into a more comprehensive conceptualization. In their framework, access to healthcare begins with the underlying health policies: the policies shape both the characteristics of the

healthcare delivery system (resources and organization) and the characteristics of the population at risk, which include individuals' predisposing factors (these determine attitudes toward and propensity to use healthcare) enabling factors (these determine capacity to utilize healthcare) as well as need factors (i.e. state of illness).[175] While the delivery system also influences the characteristics of the population at risk, both determine the two inter-related outcomes of interest: realized utilization of health services, and the satisfaction of those that utilize it.[175]

The causal logic in Andersen & Newman's framework of health utilization is similar: health utilization behaviors stem from social determinants (social healthcare norms and technological developments), which shape the characteristics of the healthcare delivery system, and the individual determinants of health utilization (i.e. predisposing, enabling, and need factors).[174] Similar to the Aday & Andersen framework, the delivery system here has an influential impact on the individual determinants of utilization, which in Andersen & Newman's model, ultimately drive the realized utilization of health services. [174]

Both of Andersen's frameworks (either separately or in combination) have guided numerous studies with various degrees of fidelity and success, and are attractive for several reasons.[176,178,179] Perhaps most important is the fact that the frameworks are the first to formally propose causal links between individual-, organizational-, and system-/contextual-level characteristics in the determination of health access and utilization. Additionally, in the case of Aday & Andersen's model, the concept of "access" is comprehensive and models various commonly-used indicators of access (the availability and means of entering the medical system, realized patient utilization, and patient

satisfaction) as being interrelated.[175] Thus, due to their comprehensive nature, the health access and utilization frameworks lend themselves well to adaptation to a wide range of health services types and settings.

While Andersen's frameworks are comprehensive to the extent of linking driving factors of health access and utilization that span across different levels of analysis, there is a lack of exploration in the underlying mechanisms of those links as well as in the components and sub-components contained in the models. However, this apparent limitation is also its strength, as it allows for it to be specifically adapted to a broad range of health services and contexts, whereby different factors and mechanisms may come into play.

Notably, Bradley et al.'s adaptation of the Andersen & Newman framework to long-term care (LTC) utilization delves deeper into the interrelationships between the patient populations' predisposing, enabling, and need factors to better understand the role of race in nursing home utilization.[176] Based on focus groups with residents of senior/assisted living homes, the authors concluded psychosocial factors – a more nuanced extension of predisposing factors in the original Andersen & Newman framework, consisting of attitudes and knowledge, social norms, and perceived control – to be key determinants of LTC use, and that they differed in important ways across racial groups.[176] Bradley et al.'s modified framework thus places greater emphasis on how population characteristics (need, enabling, and psychosocial factors) interact to influence utilization outcomes.[176]

Yabroff et al.'s adaptation was based on findings from a review of the literature

on the accessibility to components of optimal EOL care[h] among terminal cancer patients.[177] True to Aday & Andersen's framework, they found barriers to access spanning across the social-, system-, provider-, and patient-/family-level units of analyses.[177] In their adapted framework, patient- and provider-level determinants of access to optimal EOL care are influenced by the characteristics of, and the interactions between the healthcare system and the larger social context. Notably, it also highlights the explicit interaction between the patient-family unit and its providers (an element of the health system) as a key mechanism in the decision-making process for utilizing health services at the EOL.[177]

The conceptual framework used for contextualizing this dissertation (**Figure 3**) is an adaptation of Andersen et al.'s frameworks of health access and utilization, and draws from both Bradley et al.'s and Yabroff et al.'s applications to LTC and EOL care. In this adaptation, Medicare beneficiaries' utilization of hospice care proceeds from both policy (as in the Aday & Andersen version[175]) and social determinants, which encompass social norms/attitudes and medical technology[i] (as in the Andersen & Newman version[174]). In the context of hospice and EOL care (an issue that is both culturally and politically contentious and sensitive), the developments of the two components are strongly influenced by each other. For example, two key Medicare stipulations hindering hospice and palliative access – (1) that eligibility hinges on a 6-month maximum prognosis by two separate physicians, and (2) that coverage of curative treatments end for those who

[h] (1) sufficiently informed patients/families with respect to prognosis and risks/benefits of different treatment options; (2) clear and informed patient/family treatment goals; (3) services and care consistent with those goals; and (4) a holistic emphasis on quality-of-life (Yabroff & Mendelblatt, p.203).

[i] Medical technology refers to both techniques and principles used by physicians to aid their role as effective therapists to change their patients' conditions toward desirable outcomes (Andersen & Newman, p.100)

enroll in the hospice benefit – are both influenced by and feed back into prevailing and social and medical norms/perceptions. These components and their interaction subsequently shape the health delivery system in important ways that influence the access to hospice care among the terminally ill.

There are two major components functioning within the health care delivery system: the hospice environment and organizational structure, as well as the social environment, both of which vary across provider groups and across geographic locales. The hospice environment and organizational structure, which is influenced by the larger health care delivery system, include provider-specific characteristics that impact admission and care practices within each entity, such as profit-status, affiliations/contracts with nursing homes, location and setting, size, patient profiles, experience with regulatory oversight, and organizational values and policies, as well as local market characteristics including availability, competitiveness, and regulatory oversight of neighboring hospices. It is within these structures and characteristics that the hospice referral process takes places through the cross-disciplinary interaction between patients' primary physicians, hospice physicians, and other care providers. As illustrated in the conceptual framework (**Figure 3**), the communication of providers' perceptions of patient needs ultimately determine patient access to and eligibility for the Medicare hospice benefit.

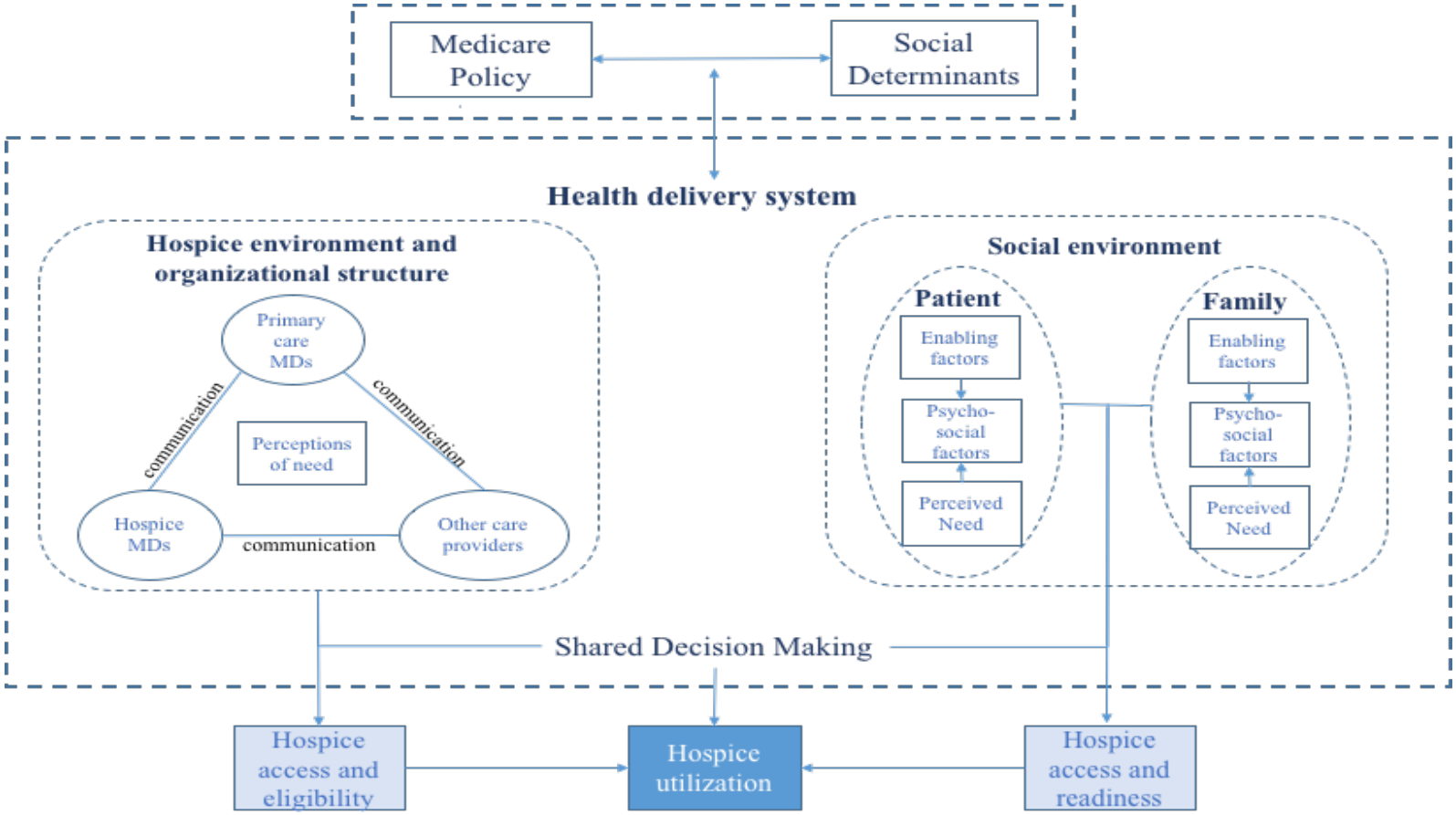
On the other side, terminally-ill patients and their family members operate within the local social environment, which shapes the demand for hospice care. Characteristics of this environment include sociodemographic and socioeconomic characteristics of the local population, which can influence the way in which individuals perceive illness, as

well as the merits and utilization of different healthcare services, including hospice. Patients and their families are modeled as separate but closely connected components, not only because patients typically seek or rely on the input of their families for end-of-life decisions, but also because the majority of hospice care in the US is provided in the home setting, which typically requires available and committed family caregivers.[3,180] In Bradley et al.'s study of LTC decision-making, patients' personal attitudes, knowledge, norms and perceived control are key psychosocial determinants that are mediated by predisposing demographic characteristics, and influenced by enabling factors and perceived need.[176] Considering the strong similarities between LTC and EOL decision-making, I have directly drawn from Bradley et al.'s model the inter-relations between enabling, psychosocial, and perceived need factors for patients and family members, which together shape their readiness to consider and access hospice enrollment, either at their own or their providers' initiative. Finally, realized enrollment in and utilization of hospice among Medicare beneficiaries are determined through the process of shared decision-making between the patient-family unit and their providers.

The IMPACT Act and the introduction of the two-tier payment system are changes in policy that are designed to directly modify hospice provider behavior and decision-making with respect to patient eligibility determinations at enrollment and throughout a patient's stay. As illustrated in the conceptual framework (**Figure 3**), the mechanism through which this occurs is through changes in the health care delivery system, which in turn elicit changes in the hospice environment and organizational characteristics within which providers make patient eligibility determinations. The extent to which provider responses may be observed are expected to be modified by the existing

organizational characteristics of each hospice, as well as the market and social environments in which hospices operate in.

Figure 3. Conceptual Framework



Source: Adapted from Aday & Anderson (1975), Bradley at el. (200), and Yabroff et al. (2004)

Chapter 2: Federal policy changes to the hospice benefit and use of hospice for persons with Alzheimer's disease and related dementias[181]

I. Introduction

Hospice is a comprehensive Medicare-covered service that supports quality-of-life for terminally-ill patients with a six-month or shorter prognosis and their family caregivers.[3] Hospice is particularly beneficial for patients with Alzheimer's disease and related dementias (ADRD) due to the disease's uniquely burdensome symptoms and resulting dependencies.[89,91,92,98–100,103,182] The proportion of hospice enrollees with ADRD as a principal diagnosis has grown considerably, from 0.2% in 1991 to over 18% in 2019,[35,127] although some of this growth may simply reflect coding changes. Notably, a large increase in the proportion of enrollees with ADRD from 2012 to 2013[183,184] likely reflects a shift toward greater use of dementia diagnosis codes resulting from the notice to exclude failure-to-thrive (FTT) and debility as qualifying principal hospice diagnoses.[185]

ADRD hospice patients are more likely to have longer stays (>6 months) than other patients due to the prolonged and variable course of ADRD, making 6-month prognostication notoriously difficult.[23,44,89,100,117,166,186,187] As the primary insurer of ADRD patients and primary payer for hospice services,[188,189] Medicare policies appreciably impact access and use of hospice by ADRD patients. Two recent changes to Medicare's hospice policies were targeted at reducing financially-motivated patient selection practices favoring those with long stays, which were previously more profitable,[17,36,41,42,125,133] and may have disproportionate impacts on ADRD patients. First, the 2014 Improving Medicare Post-Acute Care Transformation (IMPACT) Act systematized hospice audits targeting long stays. Second, in 2016, Medicare introduced

the two-tier payment system, reducing routine home care (RHC) reimbursement after the first 60 days of a stay.[40,42]

Our goal was to describe trends in the share of patients with a qualifying diagnosis of ADRD in hospice before, during, and after the IMPACT Act and implementation of the two-tier payment system, while accounting for the FTT/debility exclusion notice, which may have affected diagnosis coding practices for ADRD patients in hospices shortly before the IMPACT Act. We hypothesize that the IMPACT Act and two-tier payment change decreased new ADRD patient enrollments and total ADRD patient caseload, with more pronounced effects in for-profit hospices.

II. Methods

a. Data sources and study sample

We used the 100% limited dataset Medicare hospice claims files from 2008 to 2019. These files contain ICD-9/ICD-10 codes indicating patients' principal and contributing terminal conditions, as well as claim dates, levels, and sites of service. We next linked these to two additional data sources: (i) the master beneficiary summary/denominator files (MBSF/DN), to obtain basic patient demographics (age, gender, race), date of death, and Medicare Advantage (MA) enrollment status, and (ii) provider of service (POS) files, to obtain annual data on hospice ownership, affiliations, and employee statistics. Additionally, we used claims files to construct monthly hospice-level demographic characteristics of new enrollees, and proportion of care days provided in each month across different levels (e.g. RHC, CHC) and sites of care (e.g. home/community, skilled nursing facility). Finally, we linked to Census data and the

Area Health Resources Files (AHRF) to obtain characteristics of the county in which each hospice is located, including total county population, county demographic distributions (gender, race/ethnicity, age), total number of physicians in the county, average household income in the county, percent of county residents who live in poverty, and the county's rural-urban continuum classification.

CMS hospice billing guidelines require a separate claim for every calendar month that a beneficiary is enrolled. We constructed care episodes by combining consecutive claims with identical beneficiary and provider IDs, and identified unique episodes as starting with any new enrollment, any re-enrollment following a prior discharge, or any new claims following a break in claims exceeding 31 days. For our analyses, we included episodes beginning between July 2008 and December 2019 (N=13,812,688), and excluded episodes with missing hospice- and/or county-level covariates (11.5%); episodes of beneficiaries aged <65 or missing beneficiary demographics (5.8%); episodes with claims billed using non-sequential dates, duplicate dates, or dates inconsistent with MBSF death dates (0.7%); and episodes violating the requirement for calendar-month claims (1.5%). The final sample included 11,124,922 episodes (**Appendix Table 1**). There were no appreciable changes in patient-level or hospice-level characteristics after exclusions (**Appendix Table 2**).

b. Outcomes

We identified patients with ADRD if they had a principal or secondary diagnosis of ADRD using ICD-9 and ICD-10 codes (**Appendix Table 3**[190]). We constructed three hospice-level outcomes: (1) monthly percent of new patient enrollees with ADRD, (2) monthly percent of patient census (defined as count of all patients receiving at least one

day of care during a given month) with ADRD, and (3) monthly percent of care days provided to patients with ADRD. We refer to percent of patient census and percent of care days provided as caseload outcomes.

c. Statistical analyses

We considered the trends in each of our three outcomes over time, in relation to the FTT/debility exclusion notice published in May 2013 (to account for code-shifting towards increased use of ADRD codes), the passage/implementation of the IMPACT ACT in September/October 2014, and implementation of the two-tier payment system in January 2016, overall, and by for-profit/non-profit status.

First, we modelled trends in each outcome as parametrized in model [1] below, to estimate how each outcome changed over time:

$$Y_{ict} = \beta_0 + \beta_1 t_pp_t + \beta_2 FTT_t + \beta_3 t_FTT_t + \beta_4 IMPpass_t + \beta_5 IMPimp_t + \beta_6 t_IMPimp_t + \beta_7 newPay_t + \beta_8 t_newPay_t + \gamma + \delta(H_{it}) + \vartheta(C_{ct}) + \alpha_i + \varepsilon_{ict} \quad [1]$$

where *i* indexes hospice, *c* indexes county, *t* indexes time in months, and Y is the outcome of interest. We used linear splines to model the linear trend in our outcome over the four distinct time periods demarcated by FTT/debility exclusion notice, IMPACT Act passage/implementation, and two-tier payment implementation: *t_pp* for the pre-FTT/debility exclusion notice time period, *t_FTT* for the post-FTT/debility exclusion notice period*, t_IMPimp* for the post-IMPACT ACT period, and *t_newPay* for the post-two-tier payment system implementation period. We also included indicator terms to allow for and estimate immediate changes in our outcomes at the time of the FTT/debility exclusion notice, passage of the IMPACT Act, implementation of the IMPACT Act, and

implementation of the two-tier payment system: *FTT, IMPpass, IMPimp,* and *newPay*. We adjusted for several covariates: γ represents month fixed-effects to account for seasonality, and *H* and *C* represent time-varying hospice- and county-level characteristics. Finally, to estimate within-hospice variations across time, we included hospice fixed-effects (α).[191]

Given little impact of adjustment for covariates (**Table 4**), we also ran and plotted results from minimally adjusted versions of model [1] (adjusting only for month and hospice fixed effects) and minimally adjusted descriptive models parameterizing time as a series of indicator variables for each month starting with the month of FTT/debility exclusion notice; these plots allowed for visual representation of the trends over time and consideration of whether there was evidence of non-linear trends.

Finally, we ran stratified analyses to evaluate whether there were differential policy effects by hospice ownership status (for-profit vs. non-profit/government-owned), and tested for effect modification significance by adding interaction terms of ownership status with the time spline and policy indicator terms to model [1]. Because hospice ownership is non-time-varying for most hospices, we excluded hospice-fixed effects from this model.

d. Sensitivity analyses

We conducted a series of sensitivity analyses to assess robustness of our findings. First, because ADRD patients often have other contributing comorbidities, we repeated the analyses by classifying as ADRD patients all those with ADRD coded in (i) the principal, second, or third diagnoses codes, and (ii) the principal, second, third, or fourth

diagnoses codes. Second, for purposes of determining payment rate under the new two-tier payment system, re-enrollments within 60 days after a discharge are considered as a continuation of the prior episode of care. Thus, we used an alternative strategy to identify new enrollments, which requires any re-enrollment following a prior discharge or break in claims to occur at least 60 days apart, and repeated our analysis of trends in percent new enrollees with ADRD. Third, we repeated our analyses for all outcomes excluding data from government-owned hospices (4.4% of all hospices), which may operate fundamentally differently from privately-owned non-profit hospices. Similarly, as beneficiaries covered by Medicare Advantage (MA) may experience different terminal care and hospice referral practices to those covered by traditional fee for service (FFS) Medicare, we repeated our analyses for all outcomes excluding beneficiaries with any MA coverage (accounting for 30.9% of all episodes). Fifth, to eliminate the influence of hospices that newly open or shut down during the analytical period (July 2008 – December 2019), we repeated our analyses limiting to hospices providing care throughout the observation period. Finally, given that 2008-2009 claims only contain date of service quarter indicators rather than specific dates (which we converted to month indicators used in our primary analyses by random number generation), we repeated our analyses excluding data for hospice episodes that began prior to 2010.

This study was approved by the George Washington University Institutional Review Board. All analyses were conducted in SAS 9.4 and Stata 15.

Table 3. Summary of patient characteristics and hospice characteristics across eligible hospice episodes

	2008 [a]	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
N	383,148	802,101	839,906	873,320	909,635	944,745	949,582	992,004	1,033,985	1,099,699	1,132,558	1,164,239
Patient characteristic												
Enrollment age, mean (SD)	82 (8.2)	82.4 (8.2)	82.5 (8.3)	82.6 (8.3)	82.7 (8.4)	82.7 (8.5)	82.7 (8.5)	82.8 (8.6)	82.8 (8.6)	82.8 (8.7)	82.8 (8.7)	82.7 (8.7)
Male, %	40.5%	40.8%	40.9%	40.9%	41.2%	41.5%	41.8%	41.9%	42.1%	42.3%	42.5%	42.7%
Race/ethnicity												
White, %	88.7%	88.8%	88.7%	88.5%	88.2%	87.9%	87.7%	87.4%	86.9%	86.7%	86.5%	86.2%
Black, %	7.8%	7.7%	7.7%	7.8%	7.8%	7.9%	7.9%	7.9%	8.1%	8.1%	8.2%	8.2%
Hispanic, %	1.5%	1.5%	1.6%	1.6%	1.6%	1.7%	1.7%	1.8%	2%	2%	2%	2%
Other, %	2.0%	2.0%	2.1%	2.2%	2.3%	2.5%	2.7%	2.9%	3.1%	3.3%	3.4%	3.6%
Any MA, %	24.0%	24.4%	24.7%	25.4%	26.7%	28.1%	3%	32.1%	33%	35.2%	37.4%	39.2%
ADRD, %	16.0%	16.4%	17.2%	17.8%	18.8%	21.9%	23%	22.5%	23.5%	23.9%	24.3%	24.5%
Hospice characteristic												
Region												
Northeast, %	15.9%	16%	16.2%	16.9%	16.7%	16.5%	16.3%	16.5%	15.9%	15.8%	15.3%	14.6%
West, %	18.9%	19%	19.3%	19.9%	19.6%	20.3%	20.4%	21.1%	21%	20.9%	20.6%	20.8%
South, %	41.3%	41.2%	40.6%	39.6%	39.5%	39.4%	39.7%	38.8%	39.4%	39.4%	40.1%	40.3%
Midwest, %	23.9%	23.8%	24%	23.7%	24.1%	23.8%	23.6%	23.6%	23.7%	24%	24%	24.3%
Rurality												
Metropolitan, %	87.3%	87.4%	87.5%	87.6%	87.5%	89.1%	89.2%	89.2%	89.4%	89.3%	88.8%	89%
Urban, %	12.0%	12.0%	12.1%	12.0%	12.1%	10.5%	10.4%	10.4%	10.2%	10.3%	10.8%	10.7%
Rural, %	0.7%	0.5%	0.5%	0.4%	0.4%	0.4%	0.4%	0.4%	0.4%	0.4%	0.4%	0.4%
Ownership												
For-profit, %	43.5%	43.7%	45.5%	46.9%	48.7%	49.6%	50.5%	51.3%	51.5%	49.7%	51.5%	53.2%
Non-profit, %	54.6%	54.6%	52.8%	51.3%	49.2%	48.2%	47.5%	46.6%	46.7%	48.5%	46.7%	45.1%
Government-owned, %	1.8%	1.8%	1.8%	1.7%	2.1%	2.2%	2%	2.1%	1.8%	1.8%	1.8%	1.7%
Freestanding, %	70.7%	71.9%	73%	75%	76.9%	78.3%	80.4%	81.8%	81.6%	82.3%	82.8%	83.7%

Abbreviations: ADRD = Alzheimer's disease and related dementias; MA = Medicare Advantage; SD = Standard deviation

[a] July 2008 – December 2008 only

III. Results

Hospice episode characteristics are summarized in **Table 3**. There was a steady rise in the total number of care episodes provided (802,101 to 1,164,239), share of patients with Medicare Advantage (MA) coverage (24% to 39%), share of patients with an ADRD code (16% to 25%), and care episodes provided at for-profit hospices (44% to 53%) between 2009 and 2019. Summary characteristics of hospices in operation each year are in **Appendix Table 4**. Over the observed time period, there was substantial increase in proportion of for-profit hospices (55% to 75%).

The percent of new enrollees with ADRD increased immediately following the FTT/debility exclusion notice and continued to rise in the following months, although corresponding monthly estimates from descriptive models suggest the rate of increase slowed after seven months (**Table 4, Figure 4**). The percent of new enrollees with ADRD then dropped significantly at the month of passage (-1.42 percentage points, 95% CI: -2.13, -0.71) and month of implementation of the IMPACT Act (-1.98 percentage points, 95% CI: -2.70, -1.26) (**Table 4, Figure 4**). While it began to rise again in following months, the descriptive models suggest the pattern was not linear (**Figure 4**). Finally, there was no clear change in the percent of new enrollees with an ADRD code at the time of the change to the two-tier payment system, though the rate of increase after the two-tier payment system went into effect was slower than in the other periods considered (**Table 4**). By the end of our observation period, the percent of new enrollees with ADRD returned to a level similar to that observed immediately before the IMPACT Act passage (**Figure 4**).

Table 4. Differences in the trajectories of percent new monthly enrollees with ADRD, percent monthly patient census with ADRD, and percent care days provided to patients with ADRD coinciding with recent policy changes affecting the Medicare hospice benefit.

	Minimally adjusted [a]		Fully adjusted [b]	
	Estimate (95% CI)	**p-value**	**Estimate (95% CI)**	**p-value**
Percent new monthly enrollees with ADRD				
Pre-FTT/debility exclusion slope [c]	0.05 (0.04, 0.05)	<.001	0.05 (0.04, 0.06)	<.001
Change at FTT/debility exclusion notice	3.74 (3.36, 4.11)	<.001	3.81 (3.43, 4.18)	<.001
Post-FTT/debility exclusion slope [c]	0.08 (0.05, 0.12)	<.001	0.09 (0.05, 0.12)	<.001
Change at IMPACT passage	-1.49 (-2.22, -0.76)	<.001	-1.42 (-2.13, -0.71)	<.001
Change at IMPACT implementation	-1.87 (-2.61, -1.13)	<.001	-1.98 (-2.70, -1.26)	<.001
Post-IMPACT slope [c]	0.11 (0.07, 0.15)	<.001	0.11 (0.07, 0.15)	<.001
Change at TTP implementation	0.22 (-0.15, 0.58)	0.243	0.15 (-0.21, 0.51)	0.416
Post TTP-slope [c]	0.02 (0.01, 0.02)	<.001	0.01 (0.00, 0.02)	0.002
Percent monthly patient census with ADRD				
Pre-FTT/debility exclusion slope [c]	0.12 (0.11, 0.12)	<.001	0.12 (0.11, 0.12)	<.001
Change at FTT/debility exclusion notice	3.05 (2.82, 3.28)	<.001	3.03 (2.81, 3.26)	<.001
Post-FTT/debility exclusion slope [c]	0.12 (0.09, 0.14)	<.001	0.12 (0.10, 0.15)	<.001
Change at IMPACT passage	-0.72 (-1.15, -0.28)	0.001	-0.69 (-1.12, -0.26)	0.002
Change at IMPACT implementation	-1.49 (-1.93, -1.04)	<.001	-1.47 (-1.91, -1.03)	<.001
Post-IMPACT slope [c]	0.06 (0.03, 0.08)	<.001	0.05 (0.03, 0.07)	<.001
Change at TTP implementation	-0.34 (-0.56, -0.12)	0.002	-0.36 (-0.57, -0.15)	<.001
Post TTP-slope [c]	0.03 (0.03, 0.04)	<.001	0.03 (0.02, 0.03)	<.001
Percent monthly care days provided to patients with ADRD				
Pre-FTT/debility exclusion slope [c]	0.13 (0.13, 0.13)	<.001	0.13 (0.13, 0.14)	<.001
Change at FTT/debility exclusion notice	3.15 (2.90, 3.40)	<.001	3.12 (2.88, 3.37)	<.001
Post-FTT/debility exclusion slope [c]	0.12 (0.09, 0.14)	<.001	0.13 (0.10, 0.15)	<.001
Change at IMPACT passage	-0.53 (-1.01, -0.05)	0.031	-0.51 (-0.99, -0.04)	0.034
Change at IMPACT implementation	-1.45 (-1.94, -0.96)	<.001	-1.40 (-1.89, -0.92)	<.001
Post-IMPACT slope [c]	0.05 (0.02, 0.07)	<.001	0.04 (0.02, 0.06)	0.001
Change at TTP implementation	-0.38 (-0.62, -0.14)	0.002	-0.40 (-0.64, -0.17)	<.001
Post TTP-slope [c]	0.03 (0.03, 0.04)	<.001	0.03 (0.02, 0.03)	<.001

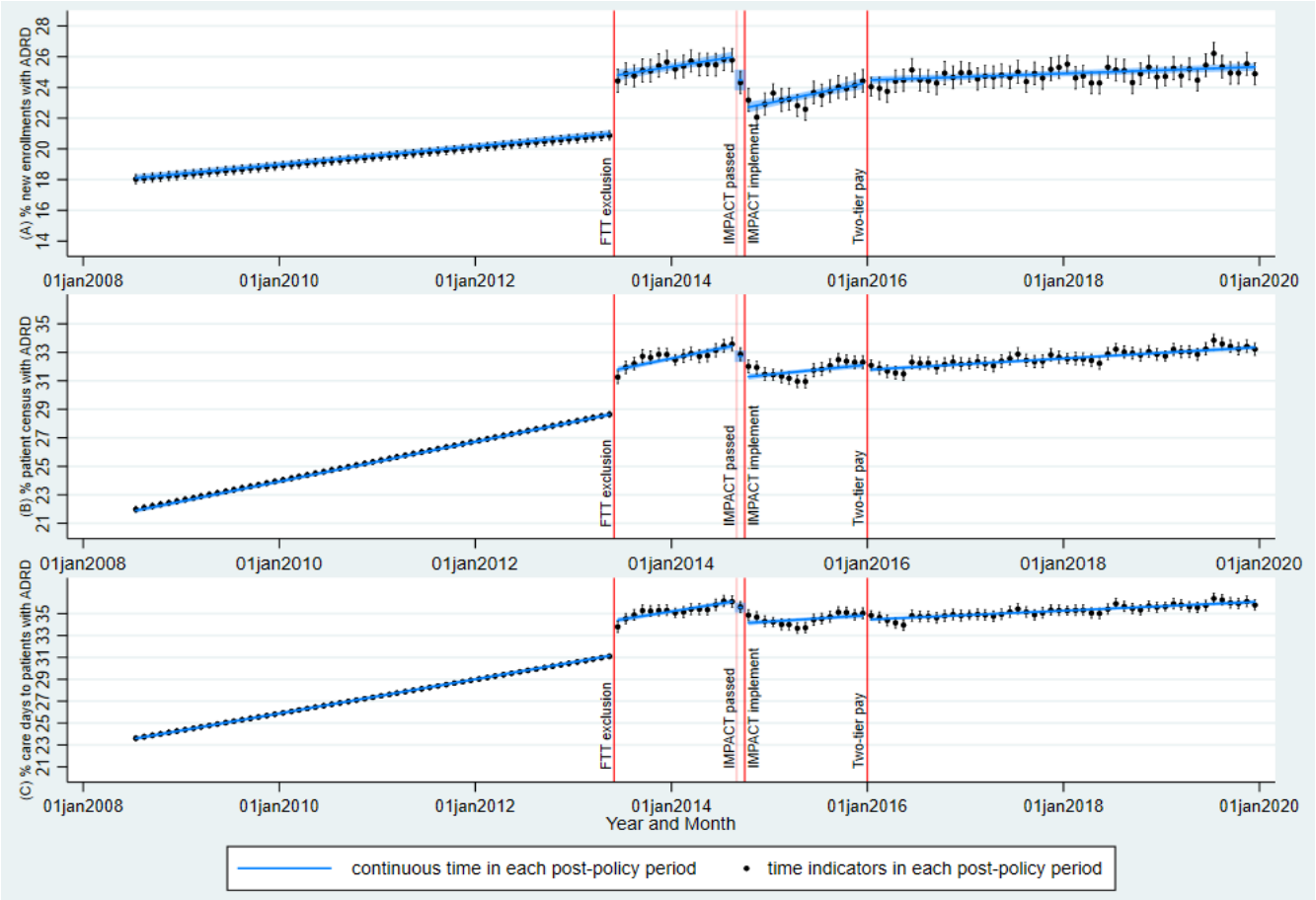
Abbreviations: FTT = Failure-to-thrive; IMPACT = Improving Medicare Post-Acute Care Transformation Act; TTP = two-tier payment

[a] Adjusted for month indicators and (absorbed) hospice fixed effects

[b] Minimally adjusted model + hospice-level covariates (ownership (for-profit vs. non-profit, free-standing vs. affiliated), total registered nurses, total employees, monthly demographic distributions (age, gender, race/ethnicity) of new enrollees, monthly percent of total care days provided at the routine home care level and continuous home care level, and monthly percent of care days provided in the community/home setting, nonskilled long-term care setting, and skilled nursing home/inpatient setting) + county-level covariates (county population, percent population over age 65 and age 85, county gender and race/ethnicity distributions, number of active physicians, rural-urban setting, percent below poverty level, median household income)

[c] Slope coefficients are direct estimates of the slope during each specified time-period.

Figure 4. Estimated trends in percent new monthly enrollees with ADRD, percent monthly patient census with ADRD, and percent care days provided to patients with ADRD, July 2008 – Dec 2019.



Abbreviations: FTT = failure-to-thrive/debility

We ran minimally adjusted models (adjusted for month indicators and hospice fixed effects) treating post-policy time splines as continuous variables (as shown in table 2), as well as minimally adjusted descriptive models treating post-policy time splines as series of binary indicators to estimate a separate coefficient for each month. Predicted trends shown in this figure (blue lines from linear models; colored circles from descriptive models) were computed by fitting model coefficients to hospice-month observations; in order to allow for clearer illustration of these trends over time, we excluded seasonality effects by ignoring the month fixed effects coefficients (i.e. setting them to 0) when computed predicted trends.

Trends in the two caseload outcomes – percent total patient census with ADRD and percent total care days provided to patients with ADRD – were similar (**Table 4, Figure 4**). Both outcomes rose following FTT/debility exclusion notice, and continued to rise in subsequent months; notably, the rates of change during the months between FTT/debility exclusion notice and IMPACT Act passage were equivalent to rates observed during the pre-FTT/debility exclusion notice period (**Table 4**). The percent of total patient census with ADRD dropped during both the month of the IMPACT Act's passage (-0.69 percentage points; 95% CI: -1.12, -0.26) and implementation (-1.47 percentage points; 95% CI:-1.91, -1.03), as did the percent of patient care days for ADRD patients (-0.51 percentage points; 95% CI: -0.99, -0.04 in the month of passage, and -1.4 percentage points; 95% CI:-1.89, -0.92 in the month of implementation) (**Table 4**). This was followed by a gradual rise for both outcomes between IMPACT act implementation and the start of the two-tier payment system. However, use of a linear trend may have masked evidence of a decline followed by recovery in both outcomes during this period (**Figure 4**). Following an immediate drop at the time of the two-tier payment system implementation, rates of increase in both outcomes after two-tier payment implementation were slower compared to those in the pre-FTT notice and pre-IMPACT Act periods (**Table 4**).

There were some differences in trends across for-profit and non-profit hospices (**Table 5**, **Figure 5**). For all outcomes, share of ADRD patients was higher in for-profit hospices than in non-profit/government-owned hospices across the whole observation period, with faster rates of increase in for-profit hospices prior to the FTT/debility exclusion notice (**Table 5**, **Figure 5**). For-profit hospices showed a significantly greater

increase in percent of new enrollees, but not other outcomes, at the time of FTT/debility exclusion notice (**Table 5**). In the months post-FTT/pre-IMPACT, all outcomes continued to increase in for-profit hospices, but exhibited no change on average in non-profit/government-owned hospices (**Table 5**, **Figure 5**). Notably, for both caseload outcomes, rate of increase was significantly faster in non-profit/government owned hospices compared to for-profit hospices after the IMPACT Act as well as after the two-tier payment implementation (**Table 5**, **Figure 5**).

Conclusions were similar across sensitivity analyses, with a few exceptions. In analyses using alternate ADRD identification strategies, or when excluding hospices that newly enter or exit the market during the observation period, the percent new enrollees with ADRD increased significantly at the time of the two-tier payment system implementation (**Appendix Table 5, Appendix Table 6**). Unlike in primary analyses, the IMPACT ACT passage was not associated with significant reductions in percent of monthly care days in analyses using alternate ADRD identification strategies, and was not associated with reductions in either caseload outcome when excluding MA enrollees (**Appendix Table 5, Appendix Table 6**).

Table 5. Differences in the trajectories of percent new monthly enrollees with ADRD, percent monthly patient census with ADRD, and percent care days provided to patients with ADRD coinciding with recent policy changes affecting the Medicare hospice benefit, estimated by fully adjusted models,[a] and stratified by for-profit vs. non-profit/government-owned hospices

	For-profit [a]		**Non-profit/Govt-owned [a]**		**For-profit vs. non-profit p-value [b]**
	Estimate (95% CI)	p-value	Estimate (95% CI)	p-value	
Percent new monthly enrollees with ADRD					
Pre-FTT/debility exclusion slope [c]	0.07 (0.06, 0.08)	<.001	0.03 (0.02, 0.04)	<.001	<.001
Change during FTT/debility exclusion notice	4.21 (3.70, 4.72)	<.001	3.10 (2.60, 3.61)	<.001	0.002
Post-FTT/debility exclusion slope [c]	0.14 (0.08, 0.19)	<.001	-0.01 (-0.06, 0.04)	0.736	<.001
Change during IMPACT passage	-1.86 (-2.84, -0.88)	<.001	-0.59 (-1.49, 0.31)	0.196	0.181
Change during IMPACT implementation	-1.88 (-2.87, -0.89)	<.001	-2.13 (-3.05, -1.21)	<.001	0.745
Post-IMPACT slope [c]	0.13 (0.08, 0.18)	<.001	0.07 (0.02, 0.12)	0.008	0.056
Change during TTP implementation	0.07 (-0.41, 0.55)	0.770	0.36 (-0.12, 0.83)	0.142	0.258
Post TTP-slope [c]	0.01 (0.00, 0.02)	0.137	0.01 (0.00, 0.02)	0.095	0.636
Percent monthly patient census with ADRD					
Pre-FTT/debility exclusion slope [c]	0.15 (0.14, 0.16)	<.001	0.08 (0.08, 0.09)	<.001	<.001
Change during FTT/debility exclusion notice	3.15 (2.86, 3.45)	<.001	2.79 (2.47, 3.11)	<.001	0.333
Post-FTT/debility exclusion slope [c]	0.2 (0.17, 0.23)	<.001	-0.01 (-0.04, 0.02)	0.462	<.001
Change during IMPACT passage	-0.79 (-1.36, -0.22)	0.007	-0.53 (-1.13, 0.07)	0.083	0.780
Change during IMPACT implementation	-1.31 (-1.88, -0.73)	<.001	-1.80 (-2.42, -1.19)	<.001	0.591
Post-IMPACT slope [c]	0.02 (0.00, 0.05)	0.104	0.10 (0.07, 0.13)	<.001	0.017
Change during TTP implementation	-0.38 (-0.66, -0.11)	0.006	-0.23 (-0.55, 0.08)	0.143	0.958
Post TTP-slope [c]	0.02 (0.01, 0.02)	<.001	0.03 (0.02, 0.04)	<.001	<.001

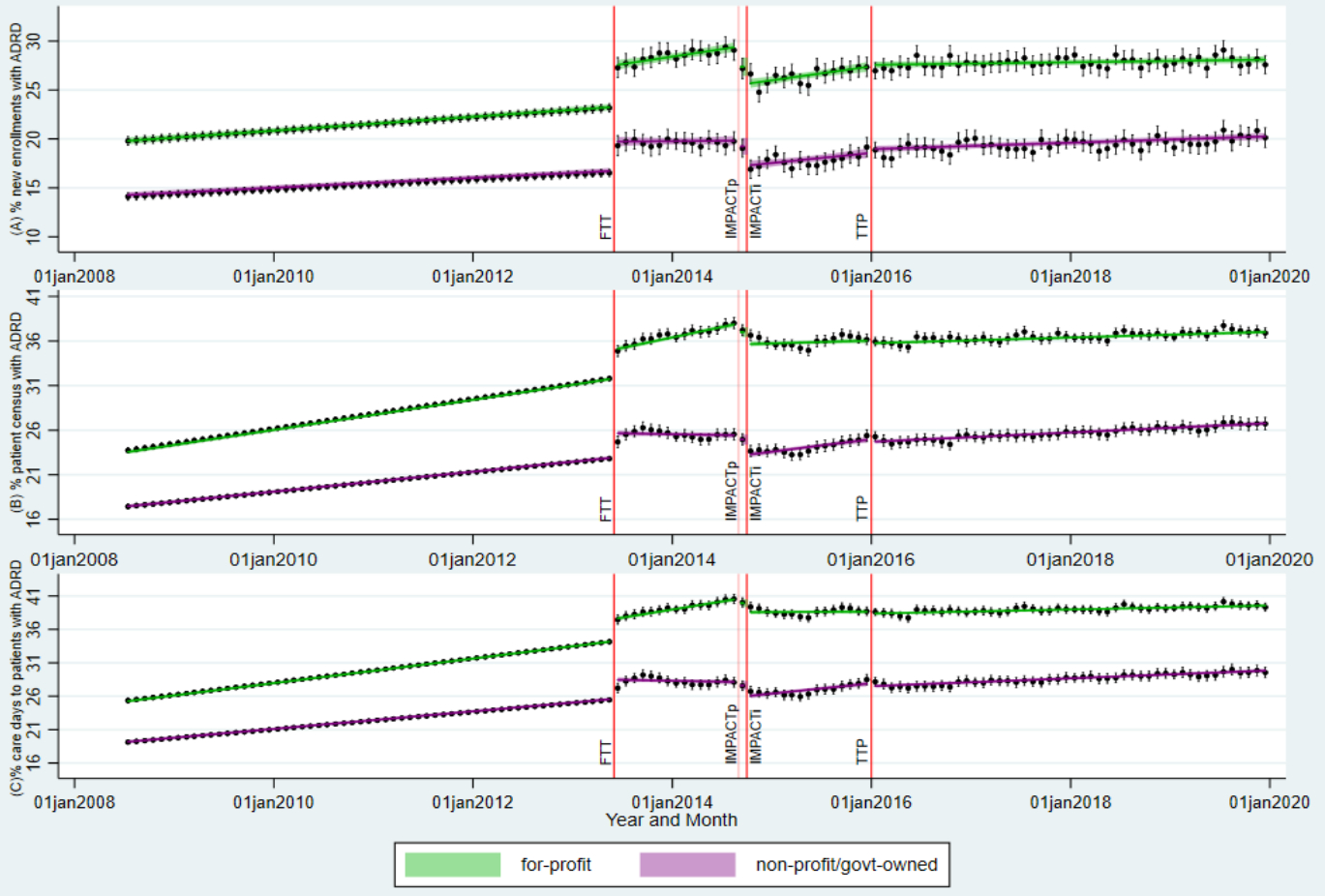
Table 5 (continued). Differences in the trajectories of percent new monthly enrollees with ADRD, percent monthly patient census with ADRD, and percent care days provided to patients with ADRD coinciding with recent policy changes affecting the Medicare hospice benefit, estimated by fully adjusted models,[a] and stratified by for-profit vs. non-profit/government-owned hospices.

	For-profit [a]		**Non-profit/Govt-owned [a]**		**For-profit vs. non-profit p-value [b]**
	Estimate (95% CI)	p-value	Estimate (95% CI)	p-value	
Percent monthly care days provided to patients with ADRD					
Pre-FTT/debility exclusion slope [c]	0.16 (0.16, 0.17)	<.001	0.10 (0.10, 0.11)	<.001	<.001
Change during FTT/debility exclusion notice	3.21 (2.89, 3.54)	<.001	2.94 (2.57, 3.30)	<.001	0.719
Post-FTT/debility exclusion slope [c]	0.20 (0.17, 0.23)	<.001	-0.01 (-0.05, 0.03)	0.545	<.001
Change during IMPACT passage	-0.50 (-1.12, 0.12)	0.113	-0.57 (-1.27, 0.12)	0.105	0.890
Change during IMPACT implementation	-1.27 (-1.9, -0.64)	<.001	-1.69 (-2.40, -0.98)	<.001	0.569
Post-IMPACT slope [c]	0.00 (-0.03, 0.03)	0.980	0.11 (0.07, 0.15)	<.001	<.001
Change during TTP implementation	-0.38 (-0.67, -0.08)	0.013	-0.35 (-0.71, 0.01)	0.055	0.365
Post TTP-slope [c]	0.01 (0.01, 0.02)	<.001	0.04 (0.03, 0.05)	<.001	<.001

Abbreviations: ADRD = Alzheimer's Disease and Related Dementias; FTT = failure-to-thrive and debility exclusion as a primary hospice diagnosis; IMPACT = Improving Medicare Post-Acute Care Transformation Act; TTP = two-tier payment

[a] Adjusted for month indicators, (absorbed) hospice fixed effects + time-varying hospice-level covariates (hospice ownership, total registered nurses, total employees, new enrollee demographic distributions (age, gender, race/ethnicity), percent care days provided at routine home care and continuous home care levels, and percent care days provided in the community/home setting, nonskilled long-term care setting, and skilled nursing home/inpatient setting) + time-varying county-level covariates (population, percent population over age 65 and over age 85, gender and race/ethnicity distributions, number of active physicians, rural-urban setting, percent below poverty level, median household income).

Figure 5. Estimated trends in percent new monthly enrollees with ADRD, percent monthly patient census with ADRD, and percent care days provided to patients with ADRD, by hospice ownership status, July 2008 – Dec 2019.



Abbreviations: FTT = failure-to-thrive/debility exclusion notice; IMPACTp = IMPACT Act passed; IMPACTi = IMPACT Act implemented; TTP = two-tier payment
We ran ownership-stratified minimally adjusted models (adjusted for month indicators and hospice fixed effects) treating post-policy time splines as continuous variables (as shown in table 2), as well as minimally adjusted descriptive models treating post-policy time splines as series of binary indicators to estimate a separate coefficient for each month. Predicted trends shown in this figure (blue lines from linear models; black circles from descriptive models) were computed by fitting model coefficients to hospice-month observations; in order to allow for clearer illustration of these trends over time, we excluded seasonality effects by ignoring the month fixed effects coefficients (i.e. setting them to 0) when computed predicted trends.

IV. Discussion

In this study, we found evidence of reduced ADRD patient hospice use with recent regulatory and payment changes to the hospice benefit.

First, there is evidence of code-shifting behavior with a steep increase in all outcomes (ADRD patient share of new enrollees, total patient census, and total care days) immediately following the FTT/debility exclusion notice.[185] This is consistent with the fact that Alzheimer's disease was among the most commonly-used contributing diagnosis in hospice patients with a principal FTT/debility diagnosis in 2012.[185] Additionally, there were similar rates of increase in percent new enrollees, and roughly identical rates of increase in caseload outcomes during the months leading up to versus in the months following the publication of notice to exclude FTT/debility. This suggests that changes in diagnosis coding following the notice to exclude FTT/debility occurred quickly and were established well before the IMPACT Act passage, thus resulting in minimal confounding by FTT/debility exclusion effects in our estimates of changes around and following the IMPACT Act and two-tier payment system.

Second, IMPACT Act passage and implementation were associated with immediate reductions, followed by an increasing trend, in all three measures of ADRD patient share. However, our descriptive analyses suggest a non-linear trend, which likely reflects an immediate risk-mitigating response by hospices to reduce risk of audits, which are administratively and financially burdensome,[154,192,193] followed by a return to an increasing trend over time. This is consistent with the idea of a "chilling effect" that reduced and delayed patient referrals,[36,78,95,152] followed by successful adaptation by hospices to the new regulatory environment.

Third, while there was negligible change in share of hospice patients with ADRD around the time of implementation of the two-tier payment system, there was a slight drop in both caseload outcomes. In the subsequent four years, all three measures rose at rates slower than those observed in the pre-FTT/debility exclusion notice period, which may reflect effects of the new regulatory and financial pressures targeting long stays.

Fourth, there was evidence of stronger policy effects in for-profit hospices compared to non-profit/government-owned hospices. Consistent with prior studies,[36,44,93,94,125,133] for-profit hospices had persistently higher shares of ADRD patients across all outcomes, and exhibited faster ADRD patient growth during the pre-IMPACT period, when long-stay patients were more profitable. Moreover, for-profit hospices had slower growth in the caseload outcomes during the post IMPACT and post two-tier payment periods, when long-stay patients became both more scrutinized by regulatory agencies and less profitable. This is consistent with profit-seeking behavior that would be expected from simulations which showed that hospice cases from 2011, when paid using the two-tier payment scheme, would have resulted in a 1.5% decline in Medicare payments at for-profits, but a 0.5% increase at non-profits, driven by longer average patient stays at for-profit hospices.[163]

Overall, our study suggests that there was a decline in hospice patients with a primary or secondary diagnosis of ADRD associated with implementation of the IMPACT Act and two-tier payment system, with more pronounced effects at for-profit hospices. This may reflect a reduction in enrollment of patients who were previously being admitted without meeting the hospice eligibility criteria for having a 6-month or shorter prognosis, as the policy intended. Alternatively, it may represent unintended

reduced access for hospice-appropriate ADRD patients due to risk-mitigating behaviors by providers to minimize the share of patients with higher likelihood of having a long-stay. It may also represent a combination of these mechanisms. As ADRD patients benefit particularly from timely access to high-quality hospice care due to the disease's unique symptom burdens, [64,88,105,157,182,194–197,89,91,92,98–100,102,103] reduced access for hospice-appropriate ADRD patients may have negatively affected the quality-of-life for patients and their families. Thus, the mechanisms through which providers have implemented change in response to the policies, and the consequences of these changes on patients and caregivers, require further research.

Our study has several limitations. First, the IMPACT Act implementation coincided with new hospice rules excluding use of certain dementia codes (senile/presenile, vascular, and unspecified dementia) as principal diagnoses that went into effect on October 1 2014.[198] However, similarity of findings across primary analyses, which use principal and secondary diagnoses codes, and sensitivity analyses allowing use of up to the fourth diagnosis code, suggests that any resulting code shifting did not greatly impact those we identified as admitted with ADRD. Second, observed trends in ADRD from claims ICD-codes may not reflect trends in true underlying ADRD patient population. The hospice population with ADRD ICD-codes clearly changed with the publication of the notice of FTT/debility exclusion. Many ADRD patients also have co-existing conditions (e.g. cancer, heart disease, etc.)[199,200] which may be easier to document and less prone to regulatory scrutiny. Thus, changes in hospices' documentation and coding practices concurrent with or in response to policy changes may conceal true changes in use of hospice by terminal ADRD patients. Additionally,

given the short proximity in which the IMPACT Act and the two-tier payment were implemented, it is unclear whether the two-tier payment would have elicited greater response had it been enacted in isolation. Finally, we were unable to account for concurrent changes in ADRD patient hospice demand, driven by the overall size of the aged Medicare-covered ADRD population.

In summary, we found evidence to suggest that recent Medicare policy changes targeting long-stay patients in hospice were associated with lasting reductions in the share of hospice patients admitted with an ADRD code compared to expectations based on pre-implementation trends. Future research should examine the mechanisms through which providers have enacted change, as well as quality of care outcomes of these changes.

Chapter 3: Association between Medicare hospice policy changes and beneficiaries' rate of live discharge and length of stay

I. Introduction

Medicare is the primary insurer for decedents 65 years and older, and pays for the large majority of hospice days provided in the United States.[17] The Medicare hospice benefit is available to beneficiaries with a prognosis of 6 months or less. Its use has grown rapidly over the past decades, with 51.6% of all Medicare-covered decedents (close to 1.6 million) enrolling in hospice prior to their death, and incurring $20.9 billion in costs to Medicare in 2019.[17] The increasing incidence of long hospice stays (>6 months) and associated costs to Medicare has prompted concerns around potentially inappropriate and financially-motivated patient selection practices favoring patients with longer projected hospice stays, who were more profitable under the original flat per diem payment system.[40–42,201] Two recent policy changes were enacted to discourage long stays: the 2014 Improving Medicare Post-Acute Care Transformation (IMPACT) Act implemented audits of hospices with high proportion of stays exceeding 180 days, and the 2016 implementation of a new two-tiered payment system that reduced per-diem rates after the first 60 days of a stay.[40–42] In response, hospice providers may have increased live discharges and/or delayed admissions to reduce patient length-of-stay (LOS).

Provider-initiated live discharges, which have been linked to financial motives rather than patient interest, are problematic because they disrupt care continuity, result in increased rates of hospitalizations and emergency room visits, and reduce quality-of-life for patients and families.[31,139,142,156–158] Similarly, evidence suggests that timely access to

hospice services and moderately long duration of hospice care are more beneficial and confer higher satisfaction than short hospice stays.[3,76,112,202–204,79,85,88,90,91,98,99,103] Thus, reduced patient length of stay due to delayed access and/or increased live discharges may be detrimental to patient care. These effects may be more pronounced in for-profit hospices than non-profit/government-owned hospices, as well as in patients who are more likely to have longer lengths of stay (e.g. Alzheimer's disease and related dementias (ADRD) patients; 38% with stays exceeding 180 days in 2013[184]), compared to patients with typically shorter lengths of stay (e.g. lung cancer patients; 9% with stays exceeding 180 days in 2013[184]).

In this paper, our goal was to describe and compare the trends in live discharges and patient LOS before, during, and after policy implementation overall, within groups with expected long hospice stays (e.g. ADRD patients) and short hospice stays (e.g., lung cancer patients), and whether the trends differed by hospice ownership status.

II. Methods

We examined trends in monthly hospice-level live discharge rates and patient LOS between 2008 and 2019. In addition to the IMPACT Act and two-tier payment, we also included the May 2013 notice to eliminate failure-to-thrive (FTT) and debility as qualifying hospice diagnoses in our analyses to account for potential loss of and diagnostic coding changes for the hospice FTT/debility population. Thus, we defined our pre-policy period as the time through May 2013, the period of policy change as that between June 2013 and December 2015, and the post-policy period as that beginning in January 2016.

a. Data sources

To assess trends in live discharges and patient LOS, we used the 100% Medicare hospice limited dataset (LDS) files spanning 2008-2019, containing ICD-9/ICD-10 diagnosis codes indicating patient primary and contributing terminal diagnoses, dates of service, as well as discharge status (i.e. alive or deceased). We supplemented the hospice LDS data with the 100% master beneficiary summary file (MBSF) LDS records from the same time period to link beneficiaries' demographic and death date information. Hospice ownership status (for-profit vs. non-profit/government), affiliations, and employee volume were linked from corresponding provider-of-service (POS) files. Finally, we compiled county characteristics for each hospice, including total population, population race, ethnicity, gender, and age distributions, average household income and percent of residents below federal poverty level, total number of practicing physicians, and rural-urban continuum classification from Census data and the Area Health Resources Files (AHRF).

b. Study samples and outcomes

We first identified unique, eligible hospice care episodes following the same process and exclusion criteria used in chapter 2. In subset analyses, we identified ADRD patients as those with a primary or secondary ICD-9/ICD-10 ADRD diagnosis code (**Appendix Table 3**), and lung/trachea cancer patients as those with a primary or secondary ICD-9/ICD-10 lung/trachea cancer diagnosis code (**Appendix Table 7**),[205] while excluding patients with both ADRD or lung/trachea cancer indicated by the first five diagnostic codes. For analyses stratified by hospice ownership, we used the POS data to identify non-profit/government-owned vs. for-profit hospices.

For live discharge analyses, we identified all episodes of care with a non-missing discharge status ending each month between July 2008 and September 2019 (N=10,539,912), and computed the monthly percent of episodes that ended in live discharge – i.e. (number of live discharges)/(number of live discharges + number of deaths) – at the hospice-level. For LOS analyses, we limited our data to episodes that had overlap with any dates between January 2010 and December 2019 (N=10,453,025). We constructed our outcome as a measure of monthly "running LOS" by first identifying all care episodes with at least one day of care provided in each month (i.e. each care episode contributes data to every calendar month that it spans). For episodes ending during a given month, we computed LOS as the number of days between the episode start and end dates; for episodes that extend beyond the month, we computed LOS as number of days between the episode start date and the last day of the month. We then summarized monthly LOS at the hospice-level, creating three outcomes: (i) mean LOS (winsorized at the 95th percentile), (ii) percent stays exceeding 60 days, and (ii) percent stays exceeding 180 days.

c. Statistical analyses

To compare pre-policy (up to the notice to exclude FTT/debility in May 2013) vs. post-policy (beginning with two-tier pay implementation in January 2016) trends, we modelled monthly outcomes during these two periods linearly. To examine month-to-month patterns in outcomes during the period of policy change between May 2013 and January 2016, we modelled outcomes descriptively using monthly binary indicators, as follows:

$$Y_{hct} = \beta_0 + \beta_1 t_prePolicy_t + \beta_2(i_PolicyChange_t) + \beta_3 i_postPolicy_t + \beta_4 t_postPolicy_t + + \boldsymbol{H}_{ht} + \boldsymbol{C}_{ct} + \sigma_h + \gamma + \varepsilon_{hct}$$

where *h* indexes hospices, *c* indexes county and *t* indexes time in months. *t_prePolicy* is a linear time spline for estimating trend slopes during the pre-policy period; *i_PolicyChange* represents a series of binary indicators for each calendar month during the period of policy change, while *i_postPolicy* is a binary variable indicating the post-policy period to allow for intercept discontinuities at the start of this period; and finally, *t_postPolicy* is a linear time spline for estimating trend slopes during the post-policy period. We adjusted for time-varying county-characteristics (***C***), time-varying hospice-characteristics (***H***), non-time-varying hospice characteristics (hospice-fixed effects (σ)), as well as seasonality (monthly indicators (γ)). We ran these analyses in our full sample as well as in each of our subsamples.

d. Sensitivity analyses

First, we used up to the first four ICD codes to identify ADRD and lung/trachea patients in subset analyses. We then repeated our analyses excluding government-owned hospices, and excluding hospices newly entering or exiting the market during the analytical period, both of which may behave differently. We also repeated our live discharge analyses excluding data from 2008-2009 due to the use of quarter indicators (rather than exact dates) in the claims, and imputing missing live discharge status (for 0.95% of episodes) based on claim end dates and MBSF death dates. Finally, because care episode day counts for purposes of determining reimbursement rates under the two-tier payment only resets with a re-admission that occurs at least 60 days after a prior discharge, we used an alternate episode identification strategy for LOS analyses, whereby

a re-enrollment must occur at least 60 days after a prior discharge or break in claims to constitute a new unique episode for a given beneficiary-provider ID pair.

This study was approved by the George Washington University Institutional Review Board. Analyses were conducted in SAS 9.4 and Stata 15.

III. Results

Patient and hospice characteristics of eligible episodes in live discharge analyses are summarized in **Table 6**. There were substantially more care episodes provided to ADRD patients (N=2,273,272) than to lung/trachea cancer patients (N=746,337) during the analytical period. Compared to lung/trachea patients, ADRD patients were older on admission (85.8 vs. 76.7), less likely to be male (31.5% vs. 51.6%), and more likely to be admitted at for-profit (56.0% vs. 41.0%) and freestanding (i.e., not part of another health organization or health system; 82.0% vs. 75.0%) hospices. Non-profit/government-owned and for-profit hospices provided a similar number of episodes of care over the whole observation period. However, compared to for-profit hospices, non-profit/government-owned hospices admitted relatively higher proportion of non-Hispanic white patients (90.2% vs. 85.0%), and provided relatively more care episodes in urban counties (12.5% vs. 9.4%) and in the Northeast (20.0% vs 12.1%) and Midwest (28.0% vs. 19.7%). Patient and hospice characteristics of eligible episodes in LOS analyses were similar (**Appendix Table 8).**

Table 6. Summary of patient characteristics and hospice characteristics across eligible hospice episodes in live discharge analyses

	Full sample	ADRD	Lung/ trachea cancer	Non-profit/ govt-owned	For-profit
N	10,539,912	2,185,076	804,194	5,401,820	5,138,092
% of full sample		20.73%	7.63%	51.25%	48.75%
Patient Characteristics					
Admission age, mean (SD)	82.6 (8.5)	85.8 (7.2)	76.7 (7.4)	82.5 (8.5)	82.8 (8.5)
Male, %	41.8%	31.5%	51.6%	42.8%	40.8%
Race/ethnicity					
Non-Hispanic white, %	87.7%	87.6%	87.8%	90.2%	85.0%
Non-Hispanic Black, %	7.9%	8.0%	8.3%	6.3%	9.6%
Hispanic. %	1.7%	2.0%	1.0%	1.1%	2.4%
Other race, %	2.7%	2.5%	2.8%	2.5%	2.9%
Had any MA coverage, %	30.4%	28.9%	32.0%	29.6%	31.1%
Primary ADRD Dx, %	20.8%	100.0%	0.0%	18.0%	23.7%
Primary lung/trachea cancer Dx, %	7.8%	0.0%	100.0%	9.0%	6.6%
Hospice/county characteristics					
Ownership					
% For-profit	48.7%	55.6%	40.8%	0.0%	100.0%
% Non-profit	49.3%	42.8%	56.9%	96.3%	0.0%
% Government-owned	1.9%	1.6%	2.2%	3.7%	0.0%
% Freestanding	78.8%	82.2%	75.3%	67.3%	90.9%
Setting rurality					
% Metropolitan	88.6%	90.0%	87.0%	87.2%	90.1%
% Urban	11.0%	9.6%	12.6%	12.5%	9.4%
% Rural	0.4%	0.4%	0.4%	0.3%	0.5%
Region					
% Northeast	16.2%	16.1%	17.2%	20.0%	12.1%
% West	20.2%	20.9%	17.5%	17.6%	22.9%
% South	39.7%	39.8%	41.3%	34.4%	45.2%
%Midwest	23.9%	23.2%	24.0%	28.0%	19.7%

Abbreviations: ADRD=Alzheimer's disease and related dementias; Dx = Diagnosis; MA=Medicare Advantage; SD=standard deviation

During the pre-policy period, the monthly percent of live discharges declined at similar rates overall (-0.13 percentage points per month, 95% CI: -0.14, -0.12), within ADRD patients (-0.10 percentage points per month, 95% CI: -0.11, -0.09), and within lung/trachea cancer patients (-0.13 percentage points per month, 95% CI: -0.14, -0.11)

(**Table 7**, **Figure 6**). These trends slowed significantly during the post-policy period, to no significant change overall over time, to -0.03 percentage points per month (95% CI: -0.04, -0.02) within ADRD patients, and to -0.04 percentage points per month (95% CI: -0.05, -0.02) within lung/trachea cancer patients (**Table 7**, **Figure 6**). Differences between pre-policy and post-policy trends were more pronounced in for-profit hospices than in non-profit/government-owned hospices; most notably, rates of decline were not significantly different between the pre- and post-policy periods within ADRD patients in non-profit/government-owned hospices **(Table 7, Figure 7**). Though for-profit hospices had faster month-to-month decline in live discharges during the pre-policy period compared to non-profit/government-owned hospices, the proportion of live discharges remained higher in for-profit hospices across the whole observation period **(Table 7, Figure 7**). Lung/trachea cancer discharge rates were consistently lower relative to other patients, and while ADRD patient discharges rates were higher than overall patient discharge rates in non-profit/government-owned hospices, they were generally lower than overall rates in for-profit hospices (**Figure 6, Figure 7**). Finally, month-to-month patterns in live discharge rates during the policy change period suggest that the trend in live discharges began to plateau at the time of IMPACT Act implementation (**Figure 6, Figure 7**).

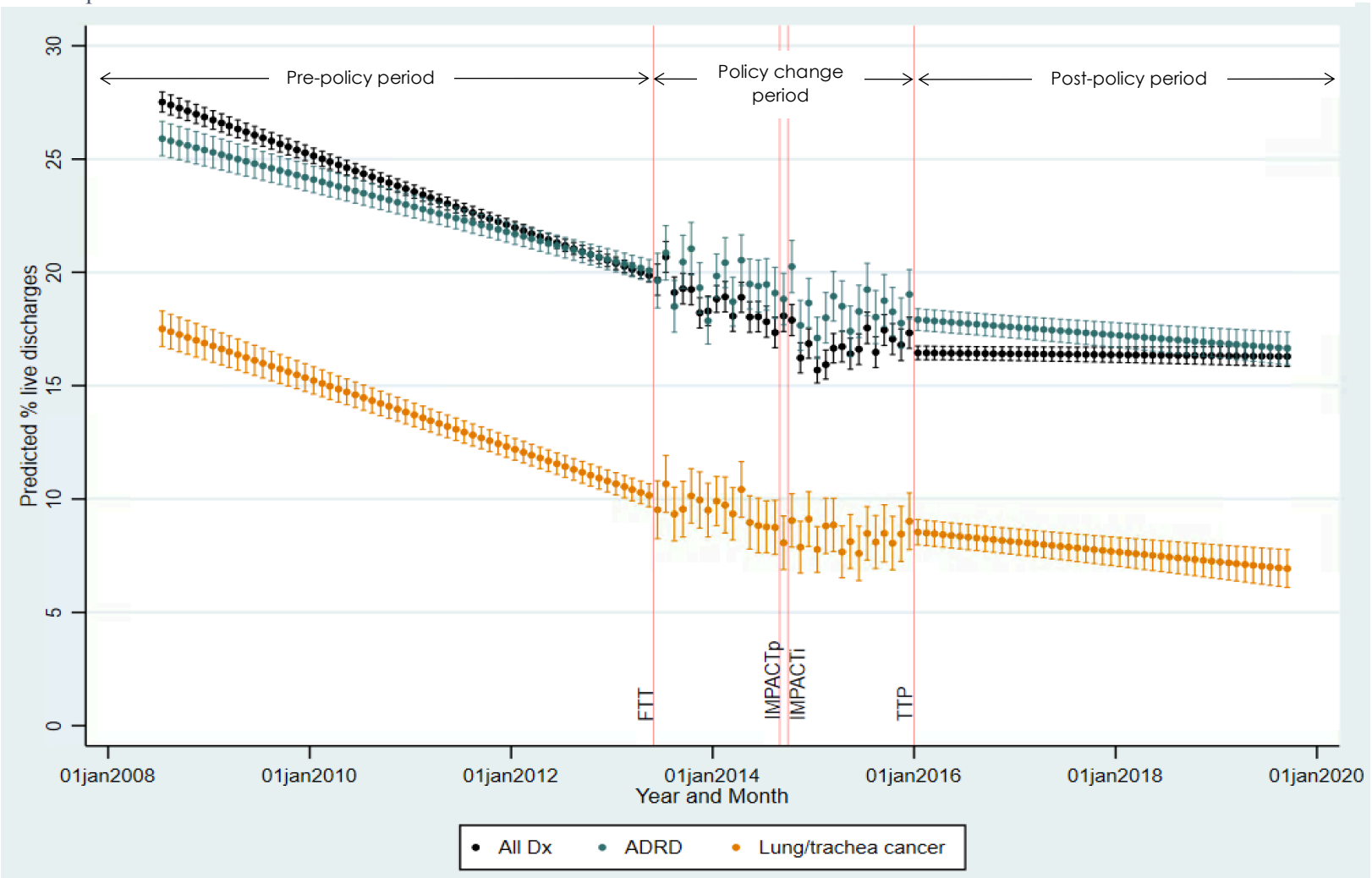
Table 7. Estimates of pre-policy and post-policy trends in live discharge rates, overall, by hospice profit status, and within ADRD and lung/trachea cancer subsamples[a]

	All hospices		Non-profit/govt-owned		For-profit	
	Estimate (95% CI)	**p-value**	**Estimate (95% CI)**	**p-value**	**Estimate (95% CI)**	**p-value**
All Diagnoses						
pre-policy slope	-0.13 (-0.14, -0.12)	<.001	-0.1 (-0.11, -0.08)	<.001	-0.16 (-0.17, -0.15)	<.001
post-policy slope	0 (-0.01, 0)	0.409	-0.04 (-0.05, -0.02)	<.001	0.01 (0, 0.02)	0.061
pre-policy vs. post-policy p-value		<.001		<.001		<.001
ADRD						
pre-policy slope	-0.1 (-0.11, -0.09)	<.001	-0.05 (-0.07, -0.03)	<.001	-0.13 (-0.15, -0.11)	<.001
post-policy slope	-0.03 (-0.04, -0.02)	<.001	-0.04 (-0.07, -0.02)	<.001	-0.02 (-0.04, 0)	0.042
pre-policy vs. post-policy p-value		<.001		0.537		<.001
Lung/trachea cancer						
pre-policy slope	-0.13 (-0.14, -0.11)	<.001	-0.11 (-0.12, -0.09)	<.001	-0.14 (-0.16, -0.12)	<.001
post-policy slope	-0.04 (-0.05, -0.02)	<.001	-0.04 (-0.06, -0.02)	<.001	-0.03 (-0.05, 0)	0.02
pre-policy vs. post-policy p-value		<.001		<.001		<.001

Abbreviations: ADRD=Alzheimer's disease and related dementias; CI=confidence interval;

[a] Estimated from models adjusted for month indicators + hospice fixed effects + hospice time-varying covariates (ownership (for-profit vs. non-profit, free-standing vs. affiliated), total registered nurses, total employees, monthly demographic distributions (age, gender, race/ethnicity) of new enrollees, monthly percent of total care days provided at the routine home care level and continuous home care level, and monthly percent of care days provided in the community/home setting, nonskilled long-term care setting, and skilled nursing home/inpatient setting) + county time-varying covariates (total population, percent population aged 65+ and 85+, gender and race/ethnicity distributions, number of active physicians, rural-urban setting, percent below poverty level, median household income)

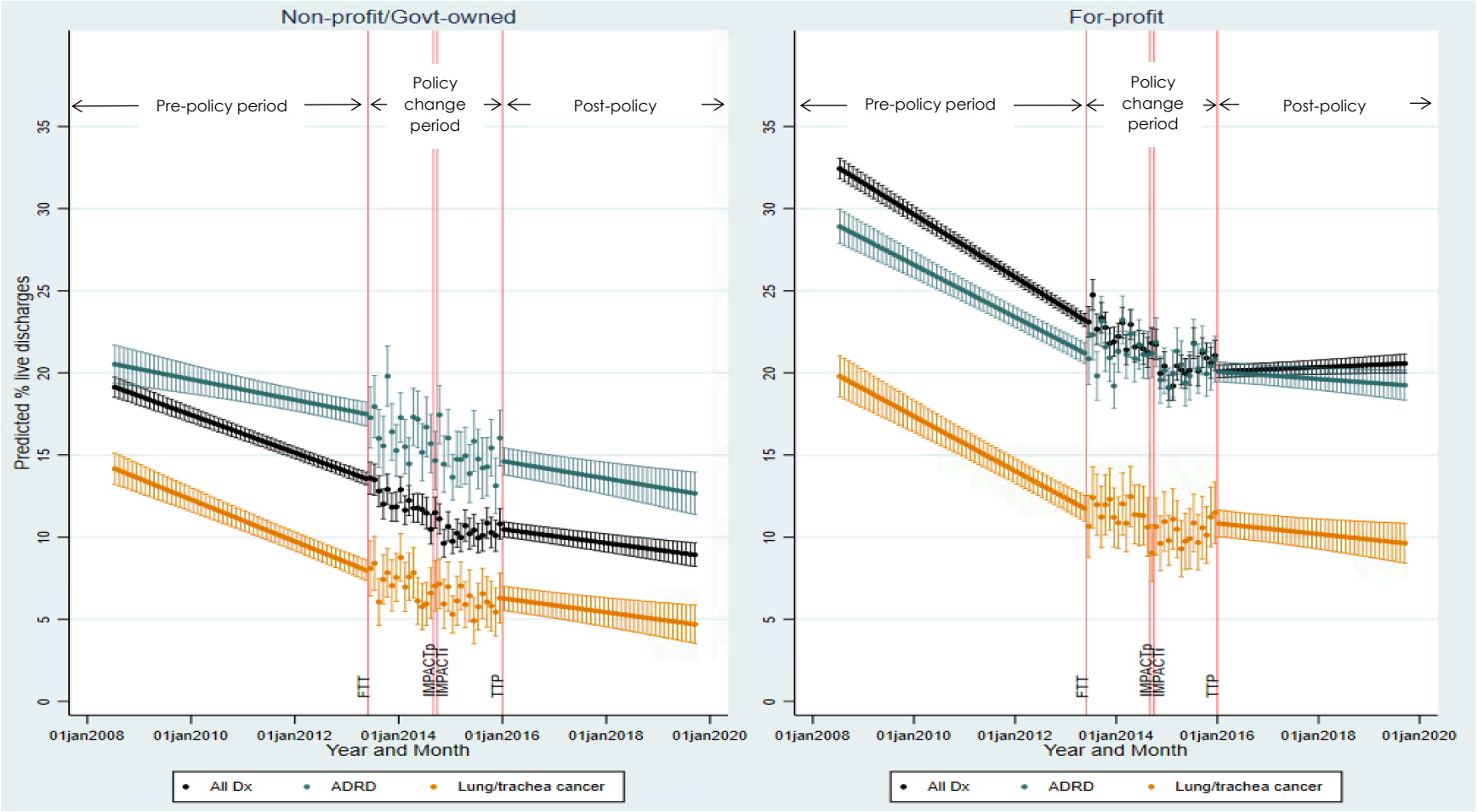
Figure 6. Predicted monthly percent of live discharges in all patients, patients with ADRD, and patients with lung/trachea cancer,[a] July 2008 – Sept 2019



Abbreviations: Dx=Diagnoses; FTT=Failure-to-thrive/debility exclusion notice; IMPACTp = IMPACT Act passage; IMPACTi = IMPACT Act implementation; TTP=two-tier pay implementation

[a] Predicted trends in this figure were estimated for the "average" hospice, by fitting fully adjusted models to each hospice-month observation, with time-varying hospice- *(H)* and ounty- (*C*) covariates set to the average sample values; additionally, month fixed effects coefficients were set to 0 in these computations in order to exclude seasonality effects and more clearly show trends over time

Figure 7. Predicted monthly percent of live discharges in all patients, patients with ADRD, and patients with lung/trachea cancer,[a] stratified by hospice ownership, July 2008 – September 2019



Abbreviations: Dx=Diagnoses; FTT=Failure-to-thrive/debility exclusion notice; IMPACTp = IMPACT Act passage; IMPACTi = IMPACT Act implementation; TTP=two-tier pay implementation

[a] Predicted trends in this figure were estimated for the "average" non-profit/govt-owned hospice and "average" for-profit hospice by fitting fully adjusted models to each hospice-month observation, with time-varying hospice- *(H)* and county- (*C*) covariates set to the average sample-specific values; additionally, month fixed effects coefficients were set to 0 in these computations in order to exclude seasonality effects and more clearly show trends over time.

Monthly mean LOS increased overall over the 2008-2019 observed period, with faster increase among ADRD patients and no significant change in lung/trachea cancer patients (**Table 8**, **Figure 8**). Monthly rates of increase were significantly faster during the post-policy period (0.41 days per month, 95% CI: 0.39, 0.42) compared to the pre-policy period (0.12 days per month, 95% CI: 0.10, 0.14) overall, as well as within ADRD patients (post-policy: 0.57 days per month, 95% CI: 0.54, 0.60; pre-policy: 0.27 days per month, 95% CI: 0.23, 0.30) (**Table 8**). For-profit mean LOS was higher in all groups (overall, ADRD, and cancer), and increased at faster rates overall and within ADRD patients, compared to non-profit mean LOS (**Figure 9**, **Table 8**). Notably, overall mean LOS declined at a slow but significant rate (-0.07 days per month, 95% CI: -0.09, -0.04) during the pre-policy period in non-profit/government-owned hospices (**Figure 9**, **Table 8**). Month-to-month patterns during the policy change period suggest that there was a temporary slowing down in the rate of increase in mean LOS in for-profit hospices overall, and especially within ADRD patients following the implementation of the IMPACT Act (**Figure 9**).

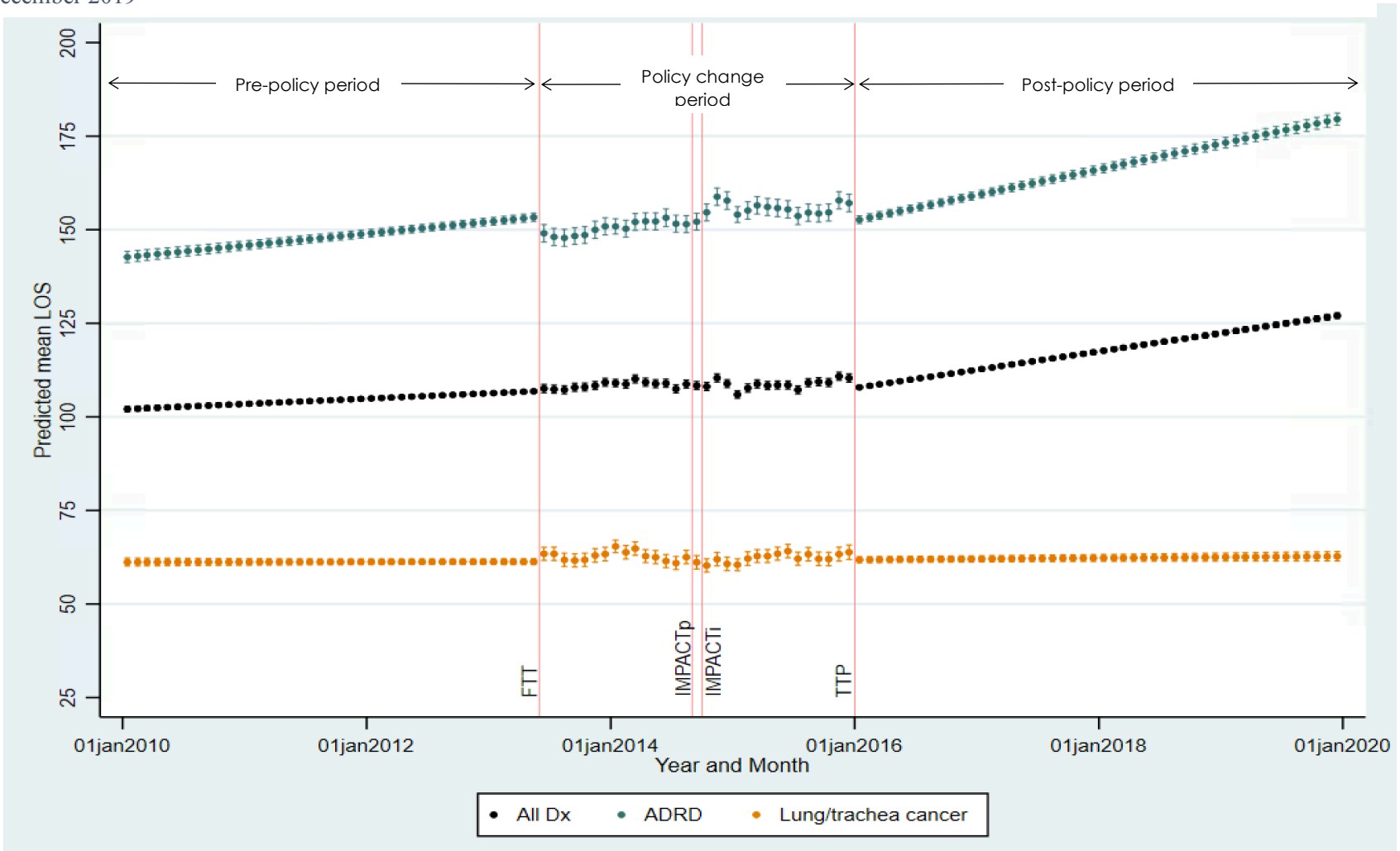
Table 8. Estimates of pre-policy and post-policy trends in mean patient length-of-stay, overall, by hospice profit status, and within ADRD and lung/trachea cancer subsamples[a]

	All hospices		Non-profit/govt-owned		For-profit	
	Estimate (95% CI)	**p-value**	**Estimate (95% CI)**	**p-value**	**Estimate (95% CI)**	**p-value**
All Diagnoses						
pre-policy slope	0.12 (0.1, 0.14)	<.001	-0.07 (-0.09, -0.04)	<.001	0.23 (0.21, 0.26)	<.001
post-policy slope	0.41 (0.39, 0.42)	<.001	0.14 (0.12, 0.16)	<.001	0.51 (0.49, 0.53)	<.001
pre-policy vs. post-policy p-value		<.001		<.001		<.001
ADRD						
pre-FTT slope	0.27 (0.23, 0.3)	<.001	0.16 (0.1, 0.22)	<.001	0.36 (0.31, 0.41)	<.001
post-TTP slope	0.57 (0.54, 0.6)	<.001	0.29 (0.24, 0.34)	<.001	0.70 (0.67, 0.74)	<.001
pre-FTT vs. post-FTT p-value		<.001		<.001		<.001
Lung/trachea cancer						
pre-FTT slope	0 (-0.02, 0.03)	0.867	-0.05 (-0.09, -0.01)	0.009	0.04 (0, 0.08)	0.057
post-TTP slope	0.02 (0, 0.04)	0.077	-0.01 (-0.05, 0.02)	0.372	0.02 (-0.01, 0.05)	0.171
pre-FTT vs. post-FTT p-value		0.228		0.082		0.44

Abbreviations: ADRD=Alzheimer's disease and related dementias; CI=confidence interval;

[a] Estimated from models adjusted for month indicators + hospice fixed effects + hospice time-varying covariates (ownership (for-profit vs. non-profit, free-standing vs. affiliated), total registered nurses, total employees, monthly demographic distributions (age, gender, race/ethnicity) of new enrollees, monthly percent of total care days provided at the routine home care level and continuous home care level, and monthly percent of care days provided in the community/home setting, nonskilled long-term care setting, and skilled nursing home/inpatient setting) + county time-varying covariates (total population, percent population aged 65+ and 85+, gender and race/ethnicity distributions, number of active physicians, rural-urban setting, percent below poverty level, median household income)

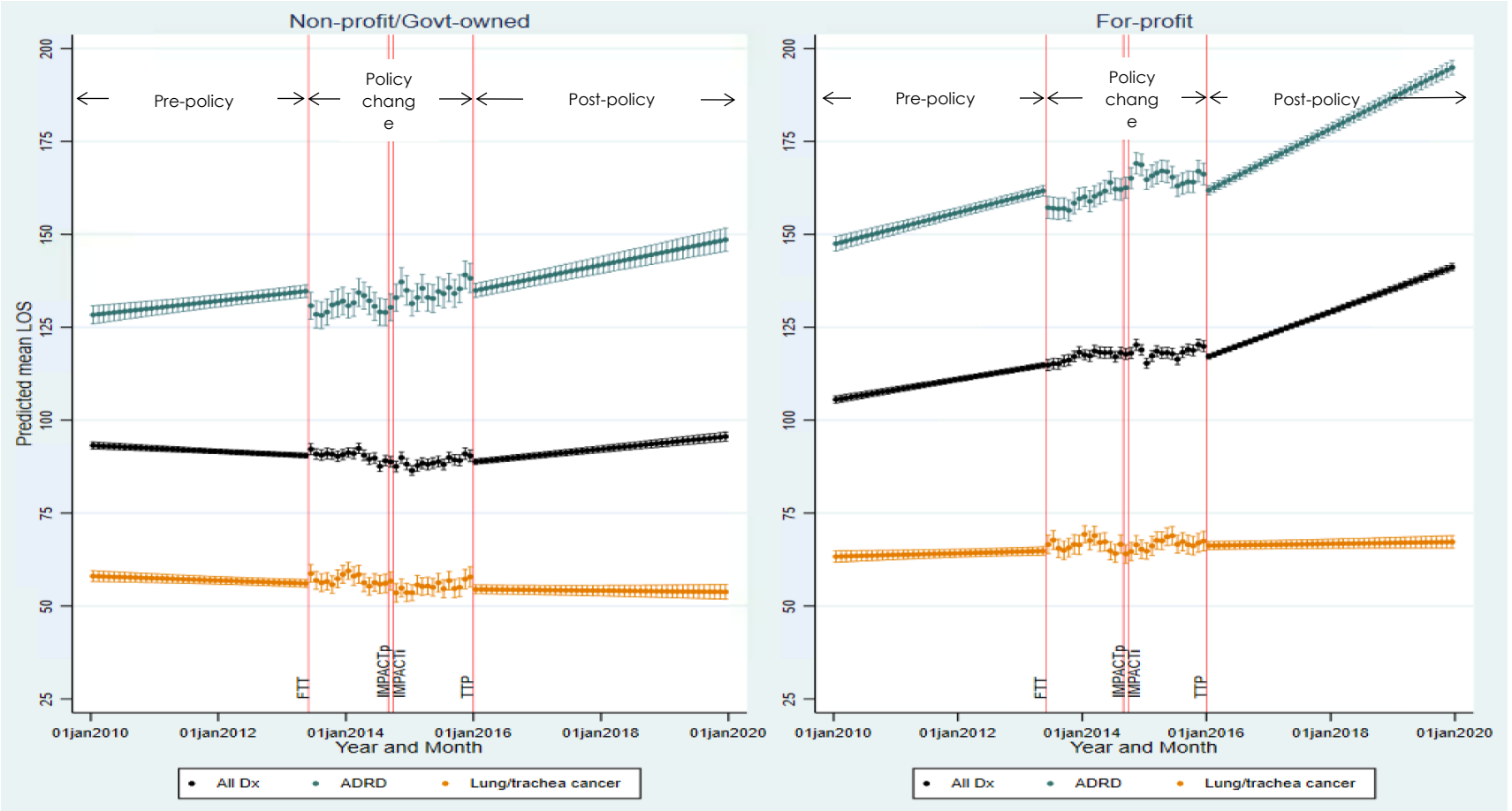
Figure 8. Predicted monthly mean length-of-stay in all patients, patients with ADRD, and patients with lung/trachea cancer,[a] January 2010 – December 2019



Abbreviations: Dx=Diagnoses; FTT=Failure-to-thrive/debility exclusion notice; IMPACTp = IMPACT Act passage; IMPACTi = IMPACT Act implementation; LOS=length-of-stay; TTP=two-tier pay implementation

[a] Predicted trends in this figure were estimated for the "average" hospice by fitting fully adjusted models to each hospice-month observation, with time-varying hospice- *(H)* and county- (*C*) covariates set to the average sample values; additionally, month fixed effects coefficients were set to 0 in these computations in order to exclude seasonality effects and more clearly show trends over time.

Figure 9. Predicted monthly mean length-of-stay in all patients, patients with ADRD, and patients with lung/trachea cancer,[a] stratified by hospice ownership, January 2010 – December 2019



Abbreviations: Dx=Diagnoses; FTT=Failure-to-thrive/debility exclusion notice; IMPACTp = IMPACT Act passage; IMPACTi = IMPACT Act implementation; LOS=length-of-stay; TTP=two-tier pay implementation

[a] Predicted trends in this figure were estimated for the "average" non-profit/govt-owned hospice and "average" for-profit hospice, by fitting fully adjusted models to each hospice-month observation, with time-varying hospice- *(H)* and county- (*C*) covariates set to the average sample-specific values; additionally, month fixed effects coefficients were set to 0 in these computations in order to exclude seasonality effects and more clearly show trends over time.

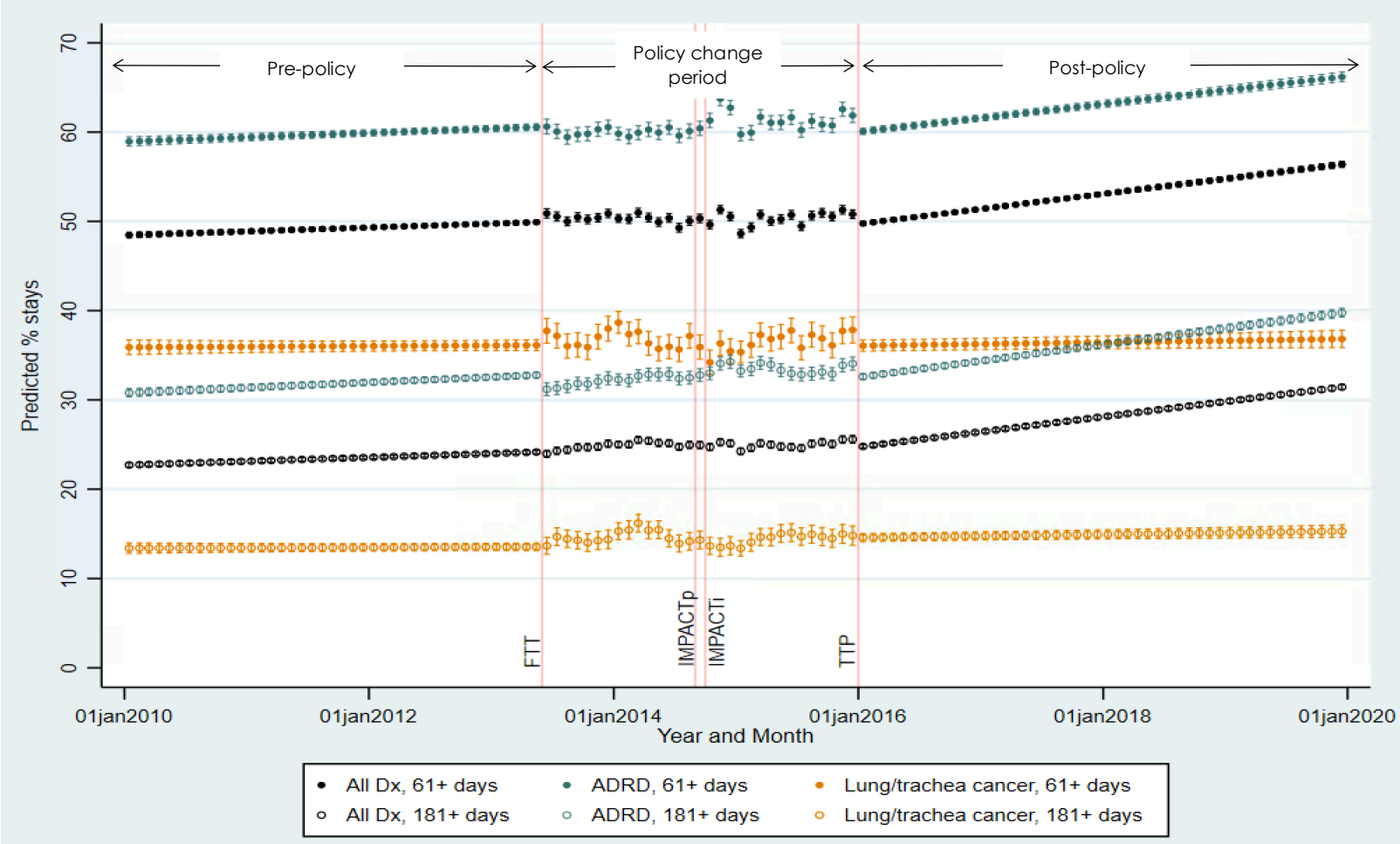
Patterns in the percent of stays exceeding 60 days and exceeding 180 days were similar to patterns in mean LOS (**Table 9**). For example, the percent of stays exceeding 60 days rose at a significantly faster rate during the post-policy period compared to the pre-policy period overall (post-policy: 0.14 percentage points per month, 95% CI: 0.14, 0.15; pre-policy: 0.04 percentage points per month, 95% CI: 0.03, 0.04), and within ADRD patients (post-policy: 0.13 percentage points per month, 95% CI: 0.12, 0.14 pre-policy: 0.04 percentage points per month, 95% CI: 0.03, 0.05) (**Table 9, Figure 10**). The percent of stays exceeding 60 days and exceeding 180 days were higher and rose faster in for-profit hospices compared to non-profit/government-owned hospices over the observed period overall (with slow but significant declines in non-profit/government-owned hospices during the pre-policy period), as well as within ADRD patients (**Table 9, Figure 11**). Rates of change in lung/trachea cancer patients were small and generally insignificant in both for-profit and non-profit/government-owned hospices (**Table 9**). Month-to-month patterns in percent long-stays during the period of policy change suggest that the percent of stays exceeding 180 days in ADRD patients at for-profit hospices declined temporarily between the IMPACT Act and two-tier payment implementation (**Figure 11**).

Table 9. Estimates of pre-policy and post-policy trends in percent stays exceeding 60 days and exceeding 180 days, overall, by hospice profit status, and within ADRD and lung/trachea cancer subsamples[a]

	All hospices		Non-profit/govt-owned		For-profit	
	Estimate (95% CI)	**p-value**	**Estimate (95% CI)**	**p-value**	**Estimate (95% CI)**	**p-value**
All Diagnoses						
Percent stays exceeding 60 days						
pre-policy slope	0.04 (0.03, 0.04)	<.001	-0.03 (-0.04, -0.02)	<.001	0.07 (0.06, 0.09)	<.001
post- policy slope	0.14 (0.14, 0.15)	<.001	0.05 (0.04, 0.06)	<.001	0.18 (0.17, 0.19)	<.001
pre-policy vs. post- policy p-value		<.001		<.001		<.001
Percent stays exceeding 180 days						
pre-policy slope	0.04 (0.03, 0.04)	<.001	-0.03 (-0.03, -0.02)	<.001	0.07 (0.06, 0.08)	<.001
post- policy slope	0.14 (0.14, 0.15)	<.001	0.05 (0.04, 0.06)	<.001	0.18 (0.17, 0.18)	<.001
pre-policy vs. post- policy p-value		<.001		<.001		<.001
ADRD						
Percent stays exceeding 60 days						
pre-policy slope	0.04 (0.03, 0.05)	<.001	0.02 (0, 0.05)	0.052	0.05 (0.04, 0.07)	<.001
post- policy slope	0.13 (0.12, 0.14)	<.001	0.06 (0.04, 0.08)	<.001	0.16 (0.15, 0.17)	<.001
pre-policy vs. post- policy p-value		<.001		0.001		<.001
Percent stays exceeding 180 days						
pre-policy slope	0.05 (0.04, 0.06)	<.001	0.02 (0, 0.04)	0.044	0.07 (0.06, 0.09)	<.001
post- policy slope	0.15 (0.14, 0.16)	<.001	0.07 (0.06, 0.09)	<.001	0.19 (0.18, 0.2)	<.001
pre-policy vs. post- policy p-value		<.001		<.001		<.001
Lung/trachea cancer						
Percent stays exceeding 60 days						
pre-policy slope	0.01 (-0.01, 0.03)	0.571	-0.02 (-0.05, 0.01)	0.163	0.02 (-0.01, 0.05)	0.15
post- policy slope	0.02 (0, 0.03)	0.065	0 (-0.03, 0.02)	0.872	0.01 (-0.01, 0.04)	0.26
pre-policy vs. post- policy p-value		0.37		0.232		0.609
Percent stays exceeding 180 days						
pre-policy slope	0 (-0.01, 0.02)	0.61	-0.03 (-0.05, -0.01)	0.001	0.03 (0.01, 0.05)	0.003
post- policy slope	0.02 (0, 0.03)	0.013	-0.01 (-0.02, 0.01)	0.513	0.02 (0, 0.04)	0.015
pre-policy vs. post- policy p-value		0.15		0.012		0.304

Abbreviations: ADRD=Alzheimer's disease and related dementias; CI=confidence interval;
[a] Estimated from models adjusted for month indicators + hospice fixed effects + hospice time-varying covariates (ownership (for-profit vs. non-profit, free-standing vs. affiliated), total registered nurses, total employees, monthly demographic distributions (age, gender, race/ethnicity) of new enrollees, monthly percent of total care days provided at the routine home care level and continuous home care level, and monthly percent of care days provided in the community/home setting, nonskilled long-term care setting, and skilled nursing home/inpatient setting) + county time-varying covariates (total population, percent population aged 65+ and 85+, gender and race/ethnicity distributions, number of active physicians, rural-urban setting, percent below poverty level, median household income)

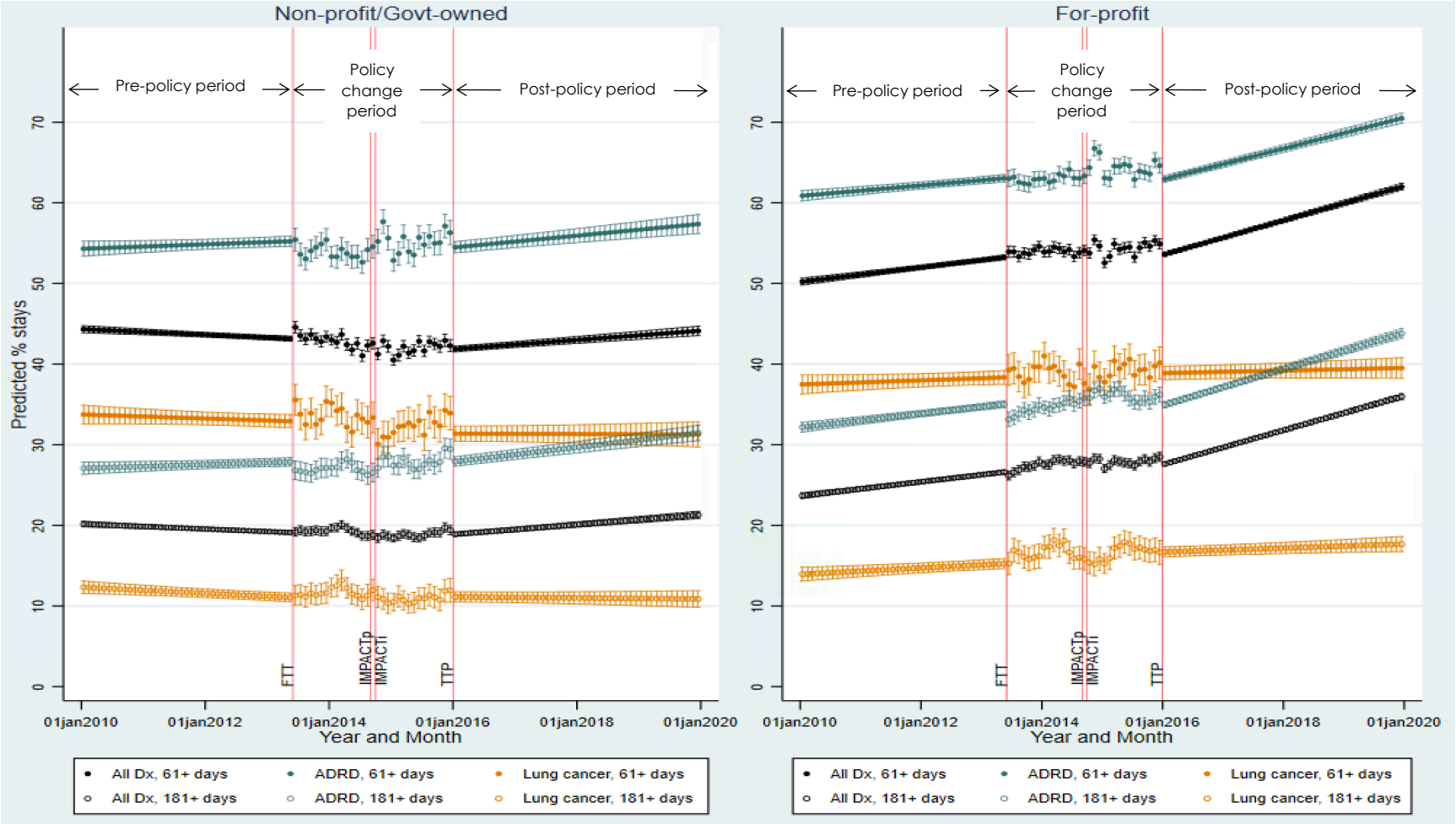
Figure 10. Predicted monthly percent stays exceeding 60 days and 180 days in all patients, patients with ADRD, and patients with lung/trachea cancer,[a] January 2010 – December 2019



Abbreviations: Dx=Diagnoses; FTT=Failure-to-thrive/debility exclusion notice; IMPACTp = IMPACT Act passage; IMPACTi = IMPACT Act implementation; TTP=two-tier pay implementation

[a] Predicted trends in this figure were estimated for the "average" hospice by fitting fully adjusted models to each hospice-month observation, with time-varying hospice- *(H)* and county- (*C*) covariates set to the average sample values; additionally, month fixed effects coefficients were set to 0 in these computations in order to exclude seasonality effects and more clearly show trends over time.

Figure 11. Predicted monthly percent stays exceeding 60 days and 180 days in all patients, patients with ADRD, and patients with lung/trachea cancer,[a] stratified by hospice ownership, January 2010 – December 2019



Abbreviations: Dx=Diagnoses; FTT=Failure-to-thrive/debility exclusion notice; IMPACTp = IMPACT Act passage; IMPACTi = IMPACT Act implementation; TTP=two-tier pay implementation

[a] Predicted trends in this figure were estimated for the "average" non-profit/govt-owned hospice and "average" for-profit hospice, by fitting fully adjusted models to each hospice-month observation, with time-varying hospice- *(H)* and county- (*C*) covariates set to the average sample-specific values; additionally, month fixed effects coefficients were set to 0 in these computations in order to exclude seasonality effects and more clearly show trends over time.

All live discharge sensitivity analyses were consistent with primary analyses (**Appendix Table 9, Appendix Table 10**). Sensitivity analyses in mean LOS and percent stays exceeding 60 and 180 days using alternate ADRD and lung/trachea cancer identification strategies (**Appendix Table 9**), excluding government-owned hospices, and using alternate episode identification (**Appendix Table 11, Appendix Table 12**) were also consistent with primary analyses. However, unlike in primary analyses, when excluding hospices newly entering or exiting the market during the observation period, the rates of change in mean LOS (**Appendix Table 11**) and percent of stays exceeding 60 and exceeding180 days **(Appendix Table 12**) during the post-policy period were similar to the those in the pre-policy period overall, and slower than those in the pre-policy period within ADRD patients. Finally, rates of change in mean LOS winsorized at the 99th percentile were faster than those in mean LOS primary analyses (winsorized at the 95th percentile), including a significant rate of increase within lung/trachea cancer patients during the post-policy period (**Appendix Table 11**).

IV. Discussion

In this work, we found evidence to suggest relatively more live discharges from hospice, but no reductions in LOS, which instead rose at faster rates, following recent regulatory and payment policy changes aimed to reduce long-stay patients in hospice compared to expectations from pre-policy trends.

The overall monthly percent of live discharges declined during the pre-policy period, but plateaued after implementation of the IMAPCT Act and exhibited no further change over time in the post-policy period. This may reflect a relatively greater willingness by providers to discharge patients and reduce risk of long stays after the

IMPACT Act went into effect. Interestingly, despite ADRD patients having substantially longer hospice stays than lung/trachea cancer patients, the rates of change in live discharge were similar between the two groups in both the pre- and post-policy periods, which suggests that changes in live discharge affected patients across the distribution of LOS similarly.

Monthly LOS increased over the analytical period overall and within ADRD patients; contrary to expectations, the rate of increase in LOS was significantly faster after implementation of the IMAPCT Act and two-tier payment system relative to observed pre-policy trends across all three measures of LOS (mean, percent stays exceeding 60 days, percent stays exceeding 180 days). This suggests that neither the IMPACT Act nor the two-tier payment system had perceivable effects on reducing long hospice stays. Additionally, the relatively stable LOS within lung/trachea cancer patients over this time period indicates that the overall rising trend in LOS is at least partially driven by changing patient mix toward greater proportion of longer-stay patients, such as those with ADRD, as shown in chapter 2. Notably, when limited to hospices in operation throughout the whole observation period, there were no significant differences in LOS rate of change between the pre- and post-policy time periods overall, and slower rate of increase during the post-policy period than during the pre-policy period within ADRD patients. This implies that the faster rate of increase during the post-policy period compared to the pre-policy period observed in primary analyses is driven by hospices that newly enter the market after 2010. In contrast, the IMPACT Act and two-tier payment policies appeared to have slowed the rate of LOS growth in ADRD patients, and potentially other patient groups with higher likelihood of long stays among hospices that

were in operation since 2010 or earlier. Finally, the faster rates of increase in mean LOS winsorized at the 99th percentile relative to rates of increase in mean LOS winsorized at the 95th percentile suggest that the fastest growth in LOS occurred at the highest end of the distribution.

Consistent with existing evidence, both rates of live discharge[141,206,207] and LOS[134,206,207] were higher in for-profit than in non-profit/government-owned hospices in our data. Our analyses also demonstrate that the post-policy stabilization in live discharge rates was driven primarily by for-profit hospices, suggesting that they exhibited greater risk-mitigating behavior, potentially due to higher baseline proportion of longer-stay patients compared to non-profit/government-owned hospices.[44,93,95,133,134] However, while there was some evidence to suggest a temporary stabilization in mean LOS and percent long stays among ADRD patients in the months following the IMPACT Act in for-profit hospices, there was no evidence that the IMPACT Act or the two-tier payment had any long-term effects on their LOS.

Overall, this work suggests that the implementation of the IMPACT Act and two-tier payment were associated with a plateauing in live discharge rates, which were previously on a declining trend during the pre-policy period. Because live discharges disrupt continuity of care, reduce patient quality-of-life, and are burdensome to patient families,[31,139,142,156–160] this relative increase in live discharges compared to pre-policy expectations may have negative implications for hospice quality of care. Furthermore, there was no corresponding decline in LOS, which instead increased at an even faster rate post-policy. This strongly suggests that the excess live discharges were occurring in patients across the spectrum of diagnoses and potential LOS, possibly due to low

correlation between Medicare hospice patient eligibility guidelines and patient 6-month mortality.[22] Our findings on LOS trends here is contrary to findings from an evaluation of a prior two-year period of heighted hospice audits under Clinton's 1995 Operation Restore Trust (ORT), which showed an associated 20% decrease in average hospice LOS.[36,153]

Our work has limitations. First, this is a descriptive analysis, and we are unable to attribute causality to observed effects associated with policy implementation due to the lack of a control group. However, more pronounced reductions in the rate of decline of live discharges in for-profit hospices compared to non-profit/government-owned hospices lends some credibility to a causal effect, given that for-profit hospices on average have higher proportions of long-stay patients,[44,93,95,133,134] and are likely to respond more strongly to regulatory and financial incentives. Second, due to the proximity between IMPACT Act and two-tier payment, interpretation of the observed effects relative to each policy independently is limited. Third, though LOS is a function of both hospice admission timing and live discharge, we were unable to directly assess whether and how the timing of admissions has changed over time and in relation to the policies, and our ability to evaluate whether initial access barriers have increased is limited based on our analyses of LOS alone.

In summary, we found that the declining trend in live discharge rates in hospice between 2008 and 2013 plateaued after implementation of the IMPACT Act, with more pronounced effects in for-profit hospices. However, the IMPACT Act and two-tier payment did not appear to have the intended effect of reducing long hospice stays as LOS increased at faster rates after implementation of the two policies relative to prior trends.

This suggests that the relative rise in live discharges was not limited to patients who would have had longer LOS, and further research is necessary to better understand the mechanisms through which hospices have responded to the new hospice regulatory and financial incentives.

Chapter 4: Hospice provider perspectives on the IMPACT Act and Medicare two-tier payment system

I. Introduction

Two recent changes were introduced to Medicare hospice to discourage financially-motivated admissions of inappropriate long-stay patients, who were more profitable than short-stay patients under prior payment rules.[30,42,44] First, the October 2014 Improving Medicare Post-Acute Care Transformation (IMPACT) Act imposed audits of hospices that exceed the pre-determined threshold for proportion of long-stay patients.[40] Second, a two-tiered hospice payment system replaced the previously used flat per-diem payment system in January 2016, reducing Medicare reimbursement for routine home care (RHC) after the first 60 days of an enrollment.[42]

Findings presented in chapters 2 and 3 suggest that these policies may have induced providers to reduce care of patients with Alzheimer's disease and related dementias (ADRD), who have the longest hospice stays of any patient group, and to increase live discharges across the board. However, it is unclear whether these access reductions were appropriate (i.e. reflecting the intention of the policies to disincentivize admissions of hospice-ineligible long-stay patients), inappropriate (i.e. reducing access for hospice-eligible patients), or a combination thereof. Given the associations between reduced hospice access with reduced quality of care and care satisfaction for terminally-ill patients and their families,[3,31,203,204,76,79,85,156–158,160,202] it is important to research the mechanisms and implications of providers' response to the IMPACT Act and new payment model. Accordingly, our goal here was to use a qualitative approach to begin

understanding these questions from the experiences and perspectives of hospice industry leaders. Additionally, as part of a broader goal to inform how Medicare end-of-life care can be improved, we also sought their perspectives on the appropriateness of and alternatives to the current Medicare hospice policies.

II. Methods

We conducted semi-structured interviews with individuals in leadership positions from hospice agencies and hospice state association leaders across the U.S.

a. Participant recruitment and data collection

We contacted all hospice state associations that were active at the time of the study, and identified key informants using publicly available information on the web or telephone calls to association contact numbers (24% completion rate). Participants representing hospice agencies were recruited using a combination of two strategies. First, we used a snowball sampling approach, leveraging personal contacts and the contacts' subsequent networks (48% completion rate). Simultaneously, using the publicly available provider-of-services (POS) files as the sampling frame, we used a maximum variation sampling approach to recruit additional participants, with the goal of maximizing diversity in hospice size, profit status, geographic location, and setting rurality (5% completion rate). Specifically, we stratified hospices across the characteristics of interest, and sampled randomly within strata defined by underrepresented characteristics in the snowball sample. We recruited potential participants via email and/or telephone calls, with up to two follow-ups if initial contact was unanswered.

Interviews were conducted via Zoom using a semi-structured interview guide, which we piloted and edited based on feedback from the first three participants. Interview questions focused on (i) participants' hospice or state experiences with the IMPACT Act and two-tier payment, particularly around issues of patient admissions and eligibility, live discharges, length of stay, and care outcomes, and (ii) participant perspectives on the appropriateness of the policies and policy alternatives. Additionally, we asked participants to comment on their experience with patients with high likelihood of having long stays in hospice (e.g. those with ADRD, respiratory and heart conditions), though many raised these discussions unprompted. Interviews lasted between 28 and 66 minutes; most lasted approximately 45 minutes.

b. Analyses

Verbatim transcriptions of recorded interviews were analyzed in Dedoose using a combined inductive-deductive thematic content analysis approach.[208] Specifically, I developed an initial codebook based on the interview guide and conceptual framework, and then used a line-by-line open coding approach to analyze the first three interviews with hospice agency leaders and the first interview with a state association representative to develop new codes and refine the codebook. Three research assistants then each coded the same four transcripts, and the codebook was further refined via team consensus. We then then independently applied the codebook to code an additional four transcripts (three agency, one association), and as a team reviewed and discussed any coding discrepancies to improve inter-coder reliability. Finally, the remaining transcripts were each analyzed by two team members using a deductive approach. Data collection and analyses were conducted concurrently until we reached data saturation.

Participants provided verbal consent prior to the start of each interview. This study was ruled exempt by the George Washington University Institutional Review Board.

III. Results

We conducted 28 interviews, including 19 with representatives from hospice agencies, and 9 with representatives from state associations, with similar representation across regions (**Table 10**). Representatives from hospice agencies were primarily Medical Directors/Chief Medical Directors, while representatives from state associations were primarily Executive Directors/Chief Executive Officers. Hospices sampled were majority non-profit (68%), independent (i.e. not affiliated with another health provider or system; 74%), and were more likely to primarily serve patients from urban and metropolitan settings (63%); most hospices also provided other services such as palliative care (84%) and home health services (53%) (**Table 11**).

Table 10. Summary of organization characteristics

Characteristic	**N (%)**
Organization Type	
Hospice agency	19 (68%)
State association	9 (32%)
Role [a]	
Medical Director/ Chief medical director (CMO)	14 (50%)
Executive Director/Chief Executive Officer (CEO)	10 (36%)
Other	8 (29%)
Region	
Northeast	5 (18%)
West	5 (18%)
South	6 (21%)
Midwest	7 (25%)
Multiple	5 (18%)

[a] Total adds up to more than 100% because some organizations had more than one participant in the interview.

Table 11. Summary of hospice agency characteristics

Characteristic	N (%)
Ownership	
Non-profit	13 (68%)
For-profit	6 (32%)
Affiliation	
None / independent	14 (74%)
Health system	3 (16%)
Hospital	2 (11%)
Locations	
One, with up to 3 satellite locations	11 (58%)
Multiple within state	4 (21%)
Multiple across states	4 (21%)
Daily Census	
< 100	4 (21%)
101-500	8 (42%)
500-1000	2 (11%)
> 1000	4 (21%)
Primary patient setting	
Urban/Metropolitan	12 (63%)
Rural	5 (26%)
Even split	2 (11%)
Provides additional services[a]	
Inpatient units	12 (63%)
Palliative care	16 (84%)
Home health care	10 (53%)
Other	11 (58%)

[a] Total adds up to more than 100% because some organizations provide multiple additional services.

a. IMPACT Act and long-stay audits

Hospices were aware of the IMPACT Act during the early stages of policy development, and received information from various avenues, including the national and their state hospice associations. Most participants described feeling concerned and nervous about the growing regulatory pressures, which, for some, began as hospice audits intensified during the years leading up to the IMPACT Act. As detailed below, hospices most commonly focused on strengthening adherence to eligibility guidelines and improving patient eligibility documentation to protect themselves against potential audits

(**Appendix Table 13,** 13.i). Several participants implied that that these changes reduced LOS, though specific statistics were rarely provided in our interviews (**Appendix Table 13,** 13.ii-13.iii). These measures were generally believed to be detrimental to patient care outcomes (**Appendix Table 13,** 13.iv).

Perceptions of policy responses and effects were not uniform across hospices. Notably, a small number of hospice and state association leaders expressed little concern around the IMPACT Act, and reported few provider-initiated changes or effects on patient access and utilization. These participants represented hospices with historically short hospice stays, strong pre-existing compliance standards, or a successful record of defending audits (**Appendix Table 13,** 13.v-16.vi). Several participants also noted that smaller, low-resource, and rural hospices were disproportionately burdened by the heightened regulatory scrutiny due to their lower financial reserves, and lower personnel and organizational capacities for adapting to new compliance and quality standards compared to large, multi-state or national hospices (**Appendix Table 13,** 13.vii). One participant also explained that as a higher proportion of the total patient census, each additional long-stay patient at a smaller hospice poses a greater audit risk than the same patient at a hospice with a higher census.

i. Initial and ongoing eligibility

Participants commonly discussed the heightened importance of adhering to local coverage determination (LCD) guidelines in making patient prognoses after the IMPACT Act, adopting a more cautious approach to patient eligibility determinations, and implementing additional processes for monitoring patient LOS, utilization, and ongoing eligibility (**Appendix Table 13,** 13.viii). However, many participants emphasized

significant challenges in prognostication, expressing frustration for LCD guidelines being too strict, and not allowing sufficient room for flexibility. This was particularly true for diagnoses with more varied symptoms and unpredictable trajectories, including Alzheimer's disease and related dementias (ADRD), frailty/debility-to-thrive or "the dwindles", chronic obstructive pulmonary disease (COPD), and heart disease (**Appendix Table 13,** 13.ix). Notably, LCD guidelines are seen as poor predictors of mortality for some patients, such as those with ADRD, further complicating eligibility prognostication (**Appendix Table 13,** 13.x). Thus, with heightened awareness around admissions eligibility under the IMPACT Act, a handful of participants described avoiding or decreasing admissions of "gray zone" patients who may appear terminal, but who do not "check all the [LCD] boxes", at least as a temporary measure while they learned how to navigate the new regulatory landscape (**Appendix Table 13,** 13.xi). Conversely, one participant explained that their hospice took the opposite approach, and was instead "very intentional" in continuing to "lean in and offer services" to gray zone after the IMPACT Act, and to not allow fears of audits create additional access barriers. Interestingly, they noted that these patients typically had "reasonable" LOS.

More commonly than reduced admissions, participants saw more live discharges as hospices increased monitoring of ongoing patient eligibility in response to the IMAPCT Act (**Appendix Table 13,** 13.xii). Measures include regular (e.g. biweekly) patient eligibility reviews by inter-disciplinary teams, systemization of patient recertification procedures and criteria, and continual internal audits of patient eligibility and documentation. With few exceptions, most participants relied strongly on evidence of ongoing decline in a patient's condition to justify their continued eligibility. However, it

was noted that decline can be subtle, plateau, or even improve temporarily with good quality care, particularly for patients with slower and more variable end-of-life trajectories, such as those with ADRD (**Appendix Table 13,** 13.xiii-xiv). Thus, increased adherence to LCD eligibility guidelines, coupled with more regular re-assessments of patient ongoing eligibility, led to earlier and more frequent discharges across many hospices.

As summarized by one participant, while hospices strive to find the balance between "keeping the appropriate patients and discharging the inappropriate patients," it is not possible to achieve perfect accuracy in prognostication, and the greater scrutiny and caution there is around eligibility, the more likely it is that eligible patients are inappropriately kept out of hospice. Several participants were frustrated over the detrimental effects of IMPACT Act-related reductions in hospice access on patients and families. They noted that denying admissions keep important and beneficial services away from dying patients for whom there are no more curative options, but who don't meet the technical hospice eligibility criteria, while delaying admissions until those criteria are met result in hospice stays that are too short and close to death for patients and families to truly benefit from the care (**Appendix Table 13,** 13.ix, 13.xv). Similarly, they described how live discharges in particular can create false hope around patient prognoses, while the simultaneous removal of hospice resources and disruption in care continuity can result in fast declines and deaths, and are burdensome to patients and families (**Appendix Table 13,** 13.xvi – 13.xvii). At least two participants cited the negative effects associated with a potential live discharge as reason to not admit patients at the onset. To ameliorate these effects, several participants described using palliative or

home health services to bridge and care for patients that are denied admission or are discharged alive (**Appendix Table 13,** 13.xviii). However, a few emphasized that compared to hospice, these alternative services are less comprehensive in coverage and reimbursement.

ii. Documentation

Most commonly, as a defense mechanism against potential audits, hospices dedicated significant efforts into strengthening documentation for demonstrating patient eligibility (**Appendix Table 13,** 13.xix). Participants described the need to "defend" all patient eligibility decisions "in writing" through "comprehensive" and "complete" documentation, and to provide a cohesive narrative to most clearly demonstrate patients' "medical necessity" for hospice to auditors (**Appendix Table 13,** 13.xx). Echoing ideas discussed in prognostication and eligibility determinations, participants highlighted the importance of documenting ongoing patient decline to justify continued eligibility. Prognostication and eligibility determination challenges were also discussed as contributing to documentation difficulties for patient groups that do not fit strictly to LCD criteria and who experience slower and more fluctuating trajectories, such as those with ADRD.

Participants noted that auditors look for very specific language in hospice documentation, and discussed the importance of using negative descriptors and adjectives, as well as objective terminology and measurements (e.g. weight loss, arm/leg circumference change, albumin levels), to build a case for eligibility in a manner that is clear and easy for auditors to follow (**Appendix Table 13,** 13.xxi). For example, some hospices began requiring documenting change and decline across specific domains at

every assessment, most commonly including the functional/ADLs, nutritional/weight/albumin, symptom control, and cognitive domains. Another common strategy cited as used in documentation was to include a comprehensive list of secondary conditions and complications, such as pneumonia, weight loss, urinary tract infections (UTIs), pressure ulcers, and eating difficulties, among others; one participant even described citing literature associating these conditions with mortality risk in their documentation. Many hospices provided staff with education and tools, including state association resources (e.g. webinars, tools and checklists, cheat sheets), to strengthen their documentation skills. Some hospices also dedicated staff time to internal documentation auditing processes to ensure compliance.

While a small fraction of participants acknowledged that IMPACT Act pressures generally facilitated better and more consistent documentation, more participants expressed feelings of frustration of having to "jump through the hoops" to continue to provide care to patients that they consider to be appropriate for hospice care. Many participants also noted the administrative burdens that the documentation requirements impose on hospices, sometimes diverting resources away from patient care (**Appendix Table 13,** 13.xxii). Importantly, two state association leaders observed that documenting objective measures of decline requires unnecessary, and sometimes burdensome procedures and tests that offer no benefit to the patient, a practice which itself is antithetical to the hospice approach to care (**Appendix Table 13,** 13.xxiii).

iii. Long-stay audits

Most hospices sampled in our study had experienced at least one audit before and/or after implementation of the IMPACT Act. While they were generally successful in

defending their cases, participants described the audit process as being time-consuming and burdensome, not only administratively as they attempt to "prove and reprove" patient appropriateness through a multi-step process, but also financially due to legal fees, fines, and settlements. Notably, payments from CMS to providers are often paused during the auditing and chart review process, which pose further financial strains, particularly when the process is prolonged due to administrative backlogs, as a handful of participants cited.

Several participants expressed frustration around the way in which audits have been conducted. Most commonly, they expressed skepticism around the private auditors contracted by CMS, who appear to have no experience or training in hospice, and who rely on simple length-of-stay numbers and certain diagnosis codes such as Alzheimer's disease to flag patients as ineligible, typically without fully evaluating the documentation, and thus resulting in unnecessary audits of appropriate patients (**Appendix Table 13,** 13.xxiv). Similarly, since participants commonly believed that CMS pays contracted auditors based on the amount that they are able to recover from provider audits, they were concerned that the auditors are inappropriately incentivized to claim as many patients as fraudulent as possible (**Appendix Table 13,** 13.xxv). For example, one state association leader observed that auditors always seem to find 20% of cases to be non-compliant across hospices, "almost like they have a target and that's what they're going for."

Many participants alluded to a sense of pressure and fear from the rise in long-stay audits, both leading up to, and following implementation of the IMPACT Act, particularly when they occurred at nearby hospices or resulted in large fines (**Appendix Table 13,** 13. xxvi). They spoke about providers being "spooked" by the audits, "afraid of some of this additional scrutiny," as well as the desire to stay out of the regulatory

"spotlight", thus necessitating a "defensive" approach to care. For example, some described feeling pressured to discharge patients once they are on service beyond six months, including patients who they still consider to be eligible (**Appendix Table 13,** 13.xxvii). The fear of regulatory scrutiny and pressure to discharge longer-stay patients have similarly prevented some providers from admitting certain patients, such as those with ADRD, who don't fit neatly within LCD criteria, and who statistically have lower likelihood of dying within six months, even if they appeared appropriate for hospice at the time of referral.

b. Two-tier payment

The financial impact of the two-tier payment was mixed across hospices depending on their patient LOS distributions. For many, the two-tier payment had little financial impact (**Appendix Table 14,** 14.i). However, hospices with shorter average LOS appeared to financially benefit from the higher payments during the first 60 days and last week of a hospice stay, while hospices with higher proportion of patients with stays exceeding 60 days, particularly those with smaller censuses, had lowered revenues as a result (**Appendix Table 14,** 14.ii-14.iii). Regardless of the financial effect, there was little indication from our participants that the new payment structure incentivized any changes in patient eligibility, admissions, or discharge decisions for financial gain (**Appendix Table 14,** 14.iv). Though two hospices suggested that their LOS had already shortened due to changes in response to previous long-stay audits by the time two-tier pay was implemented, it was unclear whether they would have similarly responded to the two-tier payment in isolation. One state association participant also described of having heard of general concerns over financially-motivated live discharges after 60 days with

the implementation of the two-tier payment system, though they did not see evidence of it in their own members (**Appendix Table 14,** 14.v). Of note, one participant experienced heightened regulatory scrutiny of discharges between days 61-180 after implementation of two-tier pay. In response, their hospice moved to earlier and more regular eligibility assessments, discharging patients as soon as they stopped meeting criteria, rather than waiting for the end of the first benefit period (90 days) to make these determinations as they did previously.

c. Policy motivators and appropriateness

i. Cost containment

Reflecting on the history of hospice, which included a number of provisions designed to contain costs when added as a benefit to Medicare, several participants attributed the heightened scrutiny on hospice to government efforts to control costs. Specifically, following the exponential growth in hospice utilization, and the concurrent growth in Medicare hospice expenditures, from "budget dust" to today's multi-billion-dollar industry dominated by for-profit agencies, they explained that the increase in regulations is understandable (**Appendix Table 15,** 15.i). Importantly, however, participants explained that even with longer patient stays and higher expenditures, hospice continues to be overall cost-reducing for Medicare by keeping patients out of emergency rooms and hospitals. Thus, focusing on hospice expenditures alone and attempting to limit access to hospice was viewed as not only detrimental for patient outcomes, but also economically inefficient (**Appendix Table 15,** 15.ii-15.iii).

ii. Fraud

Perceptions around Medicare hospice fraud and policy efforts to reduce fraud were mixed. Participants generally acknowledged that fraud exists in the industry, though few had witnessed it personally. With exception of two participants, our interviewees did not believe the problem to be very common (**Appendix Table 15,** 15.iv). Some also attributed much of what the IMPACT Act audits are targeting to issues such as subpar documentation, ignorance of the rules, "misguided intentions" in effort to continue to care for sick patients, and prognostication difficulties for patients with fluctuating trajectories, rather than intentional fraud. Importantly, one participant explained that the bigger driver behind the rise in hospice patients outliving six months is not due to fraudulent cherry-picking of patients, but rather due to the shift in the elderly terminal population enrolled in hospice from predominantly cancer patients to those with longer and more variable trajectories.

There were differences between for-profit and non-profit hospice representatives' discussions around fraud. Several interviewees representing state association leaders and non-profit hospice agencies expressed concern around the proliferation of for-profit hospice organizations, and attributed fraudulent and inappropriate behaviors, from patient-selection to marketing practices, to for-profit hospices (**Appendix Table 15,** 15.v). Profit-seeking was criticized as being fundamentally antithetical to the original goals and philosophy of hospice care, and as having damaged the public perceptions and trust in the hospice industry (**Appendix Table 15,** 15.vi-15.vii). They also explained that the prioritization of revenues and induced market competition have exacerbated incentives for more unethical behavior to gain advantages over local competitors,

particularly in non-certificate-of-needs (CON) states where the concentration of hospices can be high. For example, one participant explained that agencies who are more willing to deny admission to patients out of eligibility concerns will simply lose future referrals to their competitors. A handful of participants alluded to the higher profit margins, and the higher proportions of institutionalized patients, who are typically less costly to care for, at for-profit hospices to illustrate fundamental differences in practices between for-profit and non-profit hospices (**Appendix Table 15,** 15.viii-15.ix). Despite these perceptions however, our interviewees from for-profit and non-profit agencies described similar internal standards for policy and regulatory compliance before and after the IMPACT Act. Notably, while those from for-profit hospices generally did not comment on hospice ownership differences, one participant from a small for-profit agency acknowledged the reputation of for-profit hospices and quality concerns that rise with increasing hospice size. However, they defended their own practice, emphasizing that for-profits are not all inherently misguided, and explaining that their agency operates like a non-profit in every aspect except that they face a tax liability.

With regard to the IMPACT Act, most participants acknowledged the necessity for some enforcement and controls to disincentivize fraudulent behavior, and while a few explicitly welcomed the greater degree of scrutiny, many felt overly burdened by the audits and current regulatory climate (**Appendix Table 15,** 15.x-15.xiii). There were also mixed perceptions on how the IMPACT Act has changed auditing risk in practice: while some have seen little change from the trends in long-stay audits predating IMPACT Act, others felt a greater degree of scrutiny and increased audits. Interestingly, one state association representative observed fewer audits after the IMPACT Act in their state,

attributing it to audits being more focused on agencies with abnormal utilization. However, the more common sentiment among our interviewees was a desire for CMS to take a more targeted approach to identify and punish incompliant hospices and reduce burdens on compliant hospices (**Appendix Table 15,** 15.xiii-15.xiv). Others also suggested that regulators should shift to a greater focus on routine surveys. As well as to take a more educational, rather than punitive, approach when issues of eligibility or documentation are discovered to facilitate greater compliance.

iii. Policy effectiveness and appropriateness

Many participants expressed skepticism over the effectiveness and appropriateness of the audits of long stays for preventing or identifying fraud, and several felt that compliant hospices are being unfairly be punished for the behavior of a few bad players (**Appendix Table 15,** 15.xiii-15.xiv). One participant summarized the policies as "a lot of administrative burden for nothing." Some participants believed the policies to be ineffective because incompliant hospices will always learn to work around regulations or policies; for example, by doctoring their documentation to pass audits while continuing to admit patients inappropriately (**Appendix Table 15,** 15.xv-15.xvi). Some participants also emphasized that patient LOS is an inappropriate metric for detecting fraud or misuse. For example, they noted that good hospice care can temporarily stabilize and even improve patient condition, thus patients outliving six months on hospice can be a signal of care quality rather than fraud (**Appendix Table 15,** 15.xvii).

Perceptions around the two-tier payment were generally more neutral, and several participants applauded the two-tier payment as a sensible change that better aligns the reimbursement structure with the cost structure of providing care, and which improves

reimbursement for care of patients with short LOS. However, there were some participants who disliked its intentions and effectiveness, citing it as a form of "rate manipulation" that, similar to the IMPACT Act, punishes the whole industry over the bad behavior of a few actors. Finally, a few participants expressed skepticism over the use of the two-tier payment to disincentivize inappropriate hospice behavior (**Appendix Table 15,** 15.xviii).

Importantly, several participants criticized the policies' goals of reducing hospice access and LOS to be fundamentally at odds with the original hospice philosophy and mission, which is to maximize access to good care and maximize quality-of-life for terminally-ill patients and their families. As described in prior sections, the auditing process itself, and the defensive mechanisms that hospices have adopted in response to the IMPACT Act have detracted from good patient care. Operating in this challenging regulatory environment was described as discouraging, demoralizing, and devoid of the "joy of doing the work and service to people at the end of life" (**Appendix Table 15,** 15.xix).

d. Alternate end-of-life models

Participants overwhelmingly supported reconsideration of Medicare end-of-life care to better facilitate patient care and quality-of-life. One participant called for a complete "rehauling" and "revamping" of the Medicare hospice benefit, highlighting that it has not been updated to maintain relevancy with changes in technology and understanding of disease since the benefit's inception 40 years ago (**Appendix Table 16,** 16.i). Several participants opined that even assuming that policies such as the IMPACT

Act and two-tier pay are sensible in the context of the current Medicare hospice criteria, they still represent a misallocation of resources because the criteria themselves are fundamentally misdirected and incompatible with the goals of maximizing patient quality-of-life (**Appendix Table 16,** 16.ii). To the benefit of both patient outcomes and the Medicare budget, alternative benefit models proposed by participants primarily corresponded with extending or replacing the 6-month prognosis criteria, or implementing a concurrent care model that allows for earlier integration of palliative care to encourage, rather than to restrict, the use of hospice and palliative services (**Appendix Table 16,** 16.ii**).**

i. Six-month prognosis

Almost all participants considered the current six-month prognosis criterion and the requirement to discharge patients who respond well to hospice to be inadequate for facilitating good end-of-life care. Two participants explained that the six-month threshold itself is an "artificial" construct, originally chosen as a compromise during negotiations of the Medicare hospice benefit, and based on an "incomplete understanding of the inevitability of life" that does not allow for individuals to consider a more comfort-based approach to care before curative options are exhausted (**Appendix Table 16,** 16.iii). A number of participants also noted that dying patients are not on a "time clock" and that "dying doesn't care about a 6-month prognosis," comparing the unpredictability of patient trajectories to weather patterns to highlight the difficulty of prognosticating accurately, even for experienced hospice providers. Only one participant felt the six-month prognosis criterion to be a "good barometer of when somebody would benefit most from the comprehensiveness of hospice services," and instead advocated for

implementing an interdisciplinary geriatric palliative care program for patients who are farther out from death, as described in the next section.

Many were in favor of extending hospice eligibility to 12 months – a proposal that has been in consideration for some time – given medical advancements that allow people to live longer with a terminal illness, as well as the shift in the disease burden among Medicare hospice beneficiaries. Others criticized the prognosis- and disease-based eligibility framework to be too narrow and clinically-focused, not allowing for consideration of the benefits of hospice, including its ability to address mental, emotional, and spiritual needs, in evaluating patient appropriateness (**Appendix Table 16,** 16.iv-16.v). Similarly, some criticized the LCD guidelines for some conditions to be poorly correlated with mortality risk, further complicating and reducing hospice access (**Appendix Table 13,** 13.x). Instead, they proposed a more individualized, flexible, and need-based or plans-/goals-of-care based approach for evaluating hospice appropriateness, highlighting variation across patient needs and benefits from hospice (**Appendix Table 16,** 16.i, 16.vi-16.vii). Finally, our interviewees were generally in favor of removing the requirement to discharge patients after they meet initial eligibility, noting that patients who respond well to hospice should be celebrated, rather than punished by losing those services. To allow for longer hospice coverage, one participant suggested further lowering the daily reimbursement rate after a period of time, such as three months.

ii. Concurrent care

Another common alternative that we heard in our interviews was a model of end-of-life care that integrates interdisciplinary palliative services earlier in the disease course, potentially through a concurrent palliative or home health care model. Such a model was described to better facilitate and prepare patients for hospice, to bridge the current care needs gap between becoming terminally ill and becoming ready and eligible for hospice, and to further reduce emergency room and hospital visits towards the end of life (**Appendix Table 16,** 16.viii). Importantly, many explained that there is no reason that patients who are receiving curative treatment should not also be receiving palliative and hospice services, which are multidisciplinary and beneficial from an early stage (**Appendix Table 16,** 16.ix).

For example, some envisioned a model where palliative care is introduced early, and which grows with intensity, while curative treatment decreases in intensity, as the disease progresses, until palliative care is provided exclusively. This model would also allow for improved continuity of care and care teams by removing the distinction between palliative care and hospice care, which as one participant pointed out, is an artificial distinction borne out of Medicare reimbursement and coverage policies (**Appendix Table 16,** 16.x). Similarly, others described a lower-intensity and lower-reimbursed version of the hospice benefit - a "hospice light" program – that can be offered to patients earlier in the disease course, particularly to those with less defined trajectories. This would allow patients to receive some of benefits of hospice earlier on, while eliminating disruptive care transitions due to being admitted to and subsequently discharged from hospice. Importantly, some participants stressed the importance of

strengthening reimbursement and expanding the scope of covered Medicare palliative services to allow for these models to be viable. Interestingly, one participant cautioned against a concurrent care or "hospice light" program, highlighting a fundamental disconnect between the goals of curative versus palliative interventions that would preclude one from benefitting fully from the hospice approach to care. Instead, they advocated for a goals-of-care based approach to evaluate eligibility for traditional hospice, as described previously (**Appendix Table 16,** 16.xi).

IV. Discussion

In this study, we spoke with leaders from 28 hospice agencies and state associations to elicit their perspectives on the IMPACT Act and two-tier payment system, and its impact on provider operations, patient access and quality of care. To our knowledge, this is the first study evaluating the implications and appropriateness of these two policies based on the hospice provider experiences.

Though participants understood the need to detract fraud, they generally regarded the IMPACT Act and long-stay audits in a negative light, describing outsize financial and administrative burdens on providers, detrimental reductions in hospice access for patients, and low effectiveness in detecting and reducing fraud. With few exceptions, the scrutiny from the IMPACT Act led hospices to implement increased controls around patient prognostication, ongoing eligibility evaluation, and documentation. Coupled with fear around the heightened scrutiny, difficulties in prognostication, and LCD guidelines with low mortality predictability, many participants suggested that these changes resulted in reduced hospice access through delayed admissions, missed admissions, and/or

increased live discharges, particularly for patients with more variable symptoms and slower decline, such as those with ADRD, general frailty, COPD and CHF. These insights are consistent with our analyses of Medicare claims data, which found reduced ADRD patient hospice utilization (Chapter 2), and a relative increase in live discharges across the board following implementation of the IMPACT Act (Chapter 3). They are also consistent with prior literature citing prognostication difficulties and fear of audits as barriers to hospice access and optimal end-of-life care, particularly for ADRD patients.[22,23,31,92,95,165,166,209]

Several participants suggested that changes in admissions and live discharges likely led to shorter LOS. This was not observed in our analyses of Medicare claims data, which revealed faster rate of increase in patient LOS after implementation of the policies relative to pre-policy expectations (Chapter 3). This discrepancy may be attributed to differences between hospices represented in our study sample versus the larger hospice industry at large. For example, hospices that opted to participate in our study may have been relatively more aware of, or sensitive to industry regulatory policies. It may also indicate that hospices with reduced LOS represent only a small minority of hospices. Alternatively, the impression of shortened LOS may be inaccurate. Along with other researchers,[22] some of our participants noted the Medicare/LCD hospice eligibility guidelines to be poor predictors of six-month mortality; one participant in particular recalled typically reasonable LOS among their "gray zone" patients that began with less definitive prognoses at admission. Thus, it is possible that the access restrictions resulting from heightened LCD adherence affected all patients (rather than only patients that would

have had long stays), which would be consistent with the lack of observed reductions in LOS.

A simulation of 2011 admission patterns under the two-tier payment system revealed a 0.5% decline in average payments to for-profit hospices, compared to a 1.5% increase in average payments to non-profit hospices, driven by the longer average LOS at for-profit hospices.[163] Consistent with this simulation, our interviews revealed that hospices with longer stays experienced financial losses while hospices with shorter stays experienced financial gains from the change, though the differences did not appear to clearly fall across agency profit status in our sample. Reassuringly, there was no indication that hospices initiated any changes to adjust their census LOS for financial gain, including in hospices that experienced lost revenues.

Finally, concerning the appropriateness of and alternatives to the Medicare hospice benefit, our participants echoed the perspectives of many other end-of-life care experts and leaders.[3,23,213–215,37,54,107,109,163,210–212] Specifically, our participants criticized the disease-/clinic-based 6-month eligibility requirement for hospice eligibility to be incompatible with caring for today's terminally-ill beneficiaries, and the regulatory restrictions on hospice access and LOS to be detrimental to patients, ineffective for fraud reduction, and economically unsound. Instead, they proposed extending or replacing the 6-month prognosis with a more patient-centered approach to evaluate hospice appropriateness, or implementing a concurrent care-based model that more formally facilitates early palliative access. Variations of these proposals have been tested by different health providers and insurance plans, most prominently Aetna's concurrent care benefit for those with a 12-month prognosis or less.[3,54] They have demonstrated high

patient satisfaction, higher quality-of-life indicators, and even longer length of life, as well as lower hospital visits and healthcare costs.[3,54] Though efforts to extend Medicare hospice eligibility to 12 months have not yet been successful, CMS has begun its own experiments with concurrent care, with the extension of concurrent care coverage to Medicaid/CHIP-covered pediatric patients in 2010, and the concurrent care demonstration for Medicare beneficiaries launched in 2014.[3]

Our study is limited by participant self-selection effects, as well as participants' recall and personal biases. Notably, our participants represent only 19 out of approximately 5,000 hospices, with a low 5% completion rate from the POS sample. Because we ended data collection efforts when saturation was reached, our findings likely only reflect themes that are common to hospices that agreed to participate in the study. Nevertheless, we were able to recruit a sample of hospices representing variation across key characteristics to strengthen confidence in our findings.

In conclusion, our interviews with leaders from 28 hospice agencies and state associations across the country suggest that the IMPACT Act is generally perceived to be ineffective for deterring fraud, while increasing access barriers for patients and imposing large administrative and financial burdens on providers. Conversely, there was little indication that the two-tier payment resulted in any financially-motivated changes in hospice access or utilization. Participants generally believed the policies' focus on restricting LOS to be misdirected, instead advocating for alternative end-of-life care models that extend access to palliative care early in the disease course to improve outcomes and reduce overall costs to Medicare. These findings are important to consider

in conjunction with relevant quantitative metrics in ongoing evaluation of these policies, as well as in informing future Medicare hospice reform.

Chapter 5: Synthesis of Findings and Policy Implications

I. Synthesis of findings

The three studies conducted in this dissertation sought to begin evaluating the implications of two recent Medicare hospice benefit changes – the 2014 IMPACT Act long-stay audits and the 2016 two-tier payment system – that disincentivize hospice provider profit-seeking through care of inappropriate long-stay patients. Together, our findings suggest that there were immediate and lasting reductions in the share of hospice patients with ADRD in hospice, a relative increase in the rate of live discharges across all diagnoses, as well as delayed and reduced admissions of hard-to-prognosticate patients resulting from hospices' increased adherence to LCD eligibility guidelines.

Specifically, analyses of Medicare hospice claims data spanning 2008 – 2019 suggest that policies were associated with immediate and lasting reductions in hospice ADRD patient share, as well as a plateauing in live discharge rates, which exhibited a declining trend during the pre-policy period, across all patients. Due to the proximity of the two policies' implementation, the quantitative findings alone are insufficient for determining the extent to which the effects were driven by each of the two policies. However, our qualitative work suggests that hospices implemented stricter admissions and ongoing eligibility standards in response to the IMPACT Act, and did not make any further changes to affect patient utilization or access in response to the two-tier payment. Finally, though our quantitative data revealed more pronounced effects in for-profit compared to non-profit hospices, there were no systematic differences in response and

compliance standards shared by participants representing for-profit vs. non-profit hospices in our qualitative study, likely due to participant selection effects.

With decreased utilization of hospice by ADRD patients, coupled with a relative increase in live discharges across all patients, we expected to see a reduction in patient LOS, as intended by the two policies. Several of our participants also believed that patient LOS had been shortened as a consequence of stricter internal eligibility controls across hospices, though specific statistics were rarely provided. Interestingly, we did not see evidence in the Medicare claims data to indicate reductions in patient LOS, which in fact rose at faster rates overall, and within ADRD patients after implementation of the policies. This apparent contradiction can likely be attributed to the low correlation between LCD eligibility guidelines and patient mortality. Specifically, hospices generally enforced stricter adherence to LCD eligibility guidelines in determining initial and ongoing patient hospice appropriateness as a defense mechanism against long stay audits. However, as some participants noted, these guidelines have low accuracy for predicting death within six months for many patient types: one study found that only 35% of apparently hospice appropriate non-cancer patients who died within six months met the technical guidelines at time of admission, while another found that only 30% of patients with heart, lung, and liver conditions meeting guidelines died within 6 months.[22] In a study of ADRD patients, researchers found no significant differences in 6-month mortality between those who did and did not meet Medicare hospice criteria.[23] As such, excess access restrictions that resulted from stricter adherence to hospice eligibility likely affected patients who would have had short stays as much as patients who would have

had longer stays, which would be consistent with the lack of post-policies reduction in LOS we observed in the data.

Finally, the intention and design of the two-tier payment system was to realign hospice reimbursement rates to the U-shaped cost pattern of providing care, and to reduce the excess profitability of long-stay patients under the previously-used flat payment system. Accordingly, our qualitative work suggests that the two-tier payment increased revenues at hospices with shorter patient LOS, and decreased revenues at hospice with longer patient LOS. Interestingly, however, published statistics do not indicate a substantial reduction in the correlation between hospice LOS and profit margins: in 2015, the year before two-tier payment was implemented, hospices in the bottom quintile of long-stay patients had -8.9% margins, compared to hospices in the top quintile, which had 16.7% margins;[113] in 2016, the first year of two-tier payment implementation, hospices in the bottom quintile of long-stay patients similarly had -5.4% margins, compared to 15.0% margins at hospices in the top quintile of long-stay patients (**Table 12**).[117] This might be attributed to other differences, such as service provision, staffing, and patient profile patterns that facilitate higher efficiency in hospices with longer stays than in hospices with shorter stays. For example, studies have shown that for-profits, which had similarly longer LOS and similarly higher profit margins than non-profits in 2015 and in 2016 (**Table 12**), provide fewer services, have lower staff numbers, and admit higher proportions of patients who require lower skill care, as well as patients who reside in in facility settings.[44,93,135,136,145,216,217]

Table 12. Summary of hospice LOS and profit margins, overall and by profit status[113,117,118]

	2015	**2016**
Profit margin by hospice long-stay quintile		
Lowest	-8.9%	-5.4%
2nd	3.6%	5.8%
3rd	14.5%	14.8%
4th	20.4%	20.0%
Highest	17.6%	15.0%
Hospice margins		
For-profit	16.4%	16.8%
Non-profit	0.1%	2.7%
Patient LOS		
For-profit, mean (90th percentile)	105 (304)	106 (308)
Non-profit, mean (90th percentile)	65 (176)	66 (180)

II. Policy implications

Our research suggests that long hospice stays have not reduced following implementation of the IMPACT Act and two tier-payment. There is also little indication from our participants that fraudulent or inappropriate provider behavior has been mitigated. Additionally, average Medicare hospice spending per beneficiary who used the service was comparable between the years before (2013) and after (2017) implementation of the policies after adjusting for inflation.[118,184] As such, there is little evidence that the policies have achieved their stated goals thus far, instead overburdening hospices with new compliance expectations, and further restricting access to hospice, with what appears to be little distinction across patient LOS, at the detriment of patient quality-of-life. Importantly, reliance on patient LOS is an inaccurate metric for detecting wasteful hospice expenditures given that long LOS can indicate either potentially inappropriate care of non-terminally ill patients, or high-quality hospice care that temporarily stabilizes or improves a patient's condition; oftentimes, the line between the two scenarios is

subtle. Additionally, due to the low accuracy of LCD hospice eligibility guidelines described previously, increased adherence to these guidelines almost certainly restricted access for hospice appropriate patients, and likely as much, if not more so, than hospice inappropriate patients.

As discussed in chapter 4, access to hospice services should be enhanced, rather than restricted, both to the benefit of patient quality-of-life, and to the benefit of the Medicare budget. Consistent with much of the ongoing discussion and debate around Medicare hospice benefit reforms, our participants highlighted that the 6-month prognosis criterion is inadequate for many non-cancer patients, who experience longer periods of decline and disability, and who make up the majority of Medicare decedents today. Two potential alternatives are extending the 6-month prognosis to a 12-month prognosis, or replacing the disease- and prognosis-based eligibility criterion with a holistic, need-based, and goals-of-care based criterion. While the proposal to extend prognosis has existed for many years, it has yet to gain legislative traction. This approach would certainly allow for increased flexibility and room for error in patient prognostication, which should, in turn, extend early and timely hospice access to a greater number of patients. However, prognostication challenges will continue to exist, and updated eligibility guidelines will likely still be poor indicators of 12-month mortality for a large portion of non-cancer patients. Moreover, this approach does not eliminate the problematic pressure to discharge patients who respond well to hospice care. Alternatively, replacing a prognosis-based approach with a needs- and goals-of-care based approach to evaluate hospice appropriateness would eliminate issues of prognostication and live discharge. However, this represents a much more radical change,

requiring a fundamental shift in our understanding of end-of-life care, and is less likely to gain legislative success. Additionally, this proposal would require substantial investigation into new eligibility parameters, implications on patients and providers, as well as the complex ethical considerations around end-of-life care decision making under this new framework.

Other approaches to improve end-of-life care loosely follow a model formalizing a multidisciplinary palliative benefit that begins earlier, concurrent with curative treatments, and which ultimately "bridges" patients into hospice. A number of our participants described implementing an informal version of this as part of the response to the IMPACT Act, enrolling patients that do not meet technical hospice eligibility guidelines into their palliative or home health program. However, in order for this model to be most successful, Medicare palliative benefits would need to be strengthened, both in terms of service coverage and provider reimbursement. Additionally, this model of care would still contend with prognostication-related hospice access and discharge issues, though their consequences on patient care should be ameliorated. To more ideally facilitate EOL continuity of care, the artificial distinction between palliative care and hospice care would be eliminated, essentially creating a single multidisciplinary benefit that begins early and increases in intensity as the disease progresses. Similar to the proposal to eliminate a disease prognostication-based hospice eligibility framework, this proposal requires a greater restructuring of Medicare benefits, along with a foundational shift in how our society and medical community approaches healthcare for severely ill older adults.

While these ideas and proposals warrant further research and investigation, it is also important to consider their feasibility in the context of the Medicare program and its history. Bound by competing interests, and the result of years of political compromise, the Medicare program was designed with layers of complexity that restricted any one group or party to significantly alter its design.[218,219] Indeed, in Medicare's nearly 60-year history, changes to the program have been rare and incremental. Prior to the Affordable Care Act (ACA), only three relatively significant amendments to Medicare were legislated, each time triggered by a "bankruptcy crisis" whereby the projected years to exhaustion of the Medicare trust-fund fell to single digits.[218] Even these amendments, however, shied away from substantial reforms of the benefit structure, instead focusing on increasing regulatory control and amending provider reimbursement rate calculations to reduce wasteful and potentially fraudulent over-prescription of medical care.[218] These measures ultimately proved to be relatively ineffective for long-term cost containment.[218] The Medicare hospice benefit's 40-year history mirrors that of its parent program. As noted in previous chapters, the hospice benefit was added to Medicare with various stipulations designed to contain beneficiary end-of-life care costs. However, the proliferation of for-profit hospices and the exponential growth in Medicare hospice outlays led to concerns over wasteful and fraudulent over-use of hospice, ultimately resulting in a handful of incremental changes to the benefit in attempt to discourage this behavior. The IMPACT Act hospice stipulations and the two-tier payment are two of the most recent examples of these changes.

Based on this understanding, it is likely that any proposal to reform the Medicare hospice benefit would need to be (i) cost-saving, and (ii) relatively incremental, in order

have opportunity of legislative success. Variations of palliative-curative concurrent care models have been implemented and tested by health systems and insurance plans, and have thus far demonstrated improved patient satisfaction, higher quality-of-care and quality-of-life indicators, as well as fewer emergency room, hospital, and intensive care unit (ICU) visits and lower overall healthcare costs.[3,37,38,54] Notably, CMS has begun its own experiments with concurrent care through the 2016 Medicare Care Choices Model (MCCM), which offers beneficiaries with a 6-month or less prognosis the option to receive hospice services while continuing to receive Medicare fee-for-service covered curative care. Evaluation of the program's performance across 89 hospices from January 2016 to September 2019 found MCCM enrollees to have earlier transition to the full Medicare hospice benefit, and on average incur 29% (or $9,874) lower total per-person health expenditures in the last 90 days of life than comparable non-MCCM enrolled beneficiaries.[220] Thus, this type of concurrent care model may be possible in the near future. Unfortunately, this model does not address the inadequacy of the 6-month criteria for today's patient population, nor the challenges posed by current LCD guidelines for hospice appropriateness. Due to the lack of precedent in using any other approach, extending the criteria to a 12-month prognosis may be far more feasible than replacing it with a patient needs-/goals-based, or any other approach. Despite its shortcomings, a 12-month prognosis eligibility should allow for notably wider and more timely access to hospice care, particularly if coupled with more flexible LCD guidelines. Whether it will be more cost-saving than the current 6-month concurrent care model will require further investigation.

In summary, regulatory and payment policies to reduce inappropriate and wasteful use of healthcare services – both within the hospice benefit and the Medicare program at large – have shown little success in containing costs, or in improving the efficiency and outcomes of healthcare delivery. Efforts to restrict access to hospice have appeared to be particularly detrimental to patient outcomes and provider operations over the past decades. With a rapidly aging population and unprecedented growth in the number of chronically-ill older adults with physical and cognitive impairments, Medicare's hospice and palliative care benefits will continue to grow in use and importance over the coming decades. Thus, it is vital to investigate and consider more creative and patient-centered approaches to EOL care. The concurrent-care model appears promising for achieving legislative success, as well as for improving efficiency and outcomes, though even greater progress may be realized in combination with additional amendments to benefit terms and reimbursement structures.

Appendices

Appendix Table 1. Number and percent of hospice episode exclusions, overall and by start year

Year	Total	Exclusions, N(%)						Remaining in sample, N(%)
		Missing hospice-level covariates	Missing county-level covariates	Missing demographics or age < 65	Claim date discrepancies	Claim date and death date discrepancies	Claims with out-of-range claim dates or claim days	
Overall	13,812,688	1,453,842 (10.5%)	132,411 (1.0%)	801,101 (5.8%)	34,595 (0.3%)	59,246 (0.4%)	206,571 (1.5%)	11,124,922 (80.5%)
2008	468,799	35,602 (7.6%)	7,096 (1.5%)	29,597 (6.3%)	172 (0%)	2,005 (0.4%)	11,179 (2.4%)	383,148 (81.7%)
2009	984,837	79,964 (8.1%)	10,886 (1.1%)	58,455 (5.9%)	411 (0%)	4,536 (0.5%)	28,484 (2.9%)	802,101 (81.4%)
2010	1,040,677	94,714 (9.1%)	12,804 (1.2%)	60,822 (5.8%)	1,748 (0.2%)	11,353 (1.1%)	19,330 (1.9%)	839,906 (80.7%)
2011	1,092,856	109,024 (10%)	12,957 (1.2%)	64,915 (5.9%)	1,736 (0.2%)	10,969 (1%)	19,935 (1.8%)	873,320 (79.9%)
2012	1,137,921	119,388 (10.5%)	13,833 (1.2%)	69,498 (6.1%)	1,837 (0.2%)	6,855 (0.6%)	16,875 (1.5%)	909,635 (79.9%)
2013	1,177,293	126,300 (10.7%)	13,938 (1.2%)	71,397 (6.1%)	1,868 (0.2%)	3,450 (0.3%)	15,595 (1.3%)	944,745 (80.2%)
2014	1,189,571	134,157 (11.3%)	14,264 (1.2%)	71,056 (6.0%)	2,506 (0.2%)	3,230 (0.3%)	14,776 (1.2%)	949,582 (79.8%)
2015	1,251,076	150,616 (12%)	14,283 (1.1%)	72,381 (5.8%)	3,034 (0.2%)	3,342 (0.3%)	15,416 (1.2%)	992,004 (79.3%)
2016	1,288,323	144,446 (11.2%)	8,178 (0.6%)	73,298 (5.7%)	6,465 (0.5%)	5,334 (0.4%)	16,617 (1.3%)	1,033,985 (80.3%)
2017	1,345,534	137,588 (10.2%)	7,611 (0.6%)	75,933 (5.6%)	3,477 (0.3%)	4,453 (0.3%)	16,773 (1.2%)	1,099,699 (81.7%)
2018	1,396,326	154,200 (11%)	8,092 (0.6%)	76,508 (5.5%)	5,923 (0.4%)	2,001 (0.1%)	17,044 (1.2%)	1,132,558 (81.1%)
2019	1,439,475	167,843 (11.7%)	8,469 (0.6%)	77,241 (5.4%)	5,418 (0.4%)	1,718 (0.1%)	14,547 (1.0%)	1,164,239 (80.9%)

Appendix Table 2. Characteristics of hospice episodes before and after exclusions[a]

	All episodes	Exclude episodes missing hospice-covariates	Exclude missing county covariates	Exclude age < 65 or missing demographic	Exclude claim date and death date discrepancies	Exclude out-of-range claim dates or claim days (remaining claims)
N	13,812,688	12,358,846	12,226,435	11,425,334	11,331,493	11,124,922
Patient age at enrollment, mean (SD)	81 (10.5)	81 (10.5)	81 (10.5)	82.7 (8.5)	82.7 (8.5)	82.7 (8.5)
Male patients, %	42.50%	42.40%	42.40%	41.60%	41.60%	41.70%
Patient race/ethnicity						
White, %	86.70%	86.50%	86.80%	87.50%	87.50%	87.50%
Black, %	8.50%	8.50%	8.50%	8.00%	8.00%	7.90%
Hispanic, %	2.00%	2.10%	1.80%	1.80%	1.80%	1.80%
Other, %	2.80%	2.90%	2.80%	2.80%	2.80%	2.80%
Patient had any MA coverage, %	30.90%	30.90%	30.60%	30.90%	30.90%	30.90%
Patient with ADRD, %	20.50%	20.50%	20.40%	21.50%	21.50%	21.40%
Region						
Northeast, %	15.60%	15.60%	15.70%	15.90%	15.90%	16.00%
West, %	20.10%	20.00%	20.10%	20.40%	20.40%	20.30%
South, %	40.60%	40.70%	40.50%	40.00%	40.00%	39.80%
Midwest, %	23.70%	23.60%	23.70%	23.80%	23.80%	23.90%
Rurality						
Large metro, %	88.50%	88.50%	88.40%	88.60%	88.60%	88.60%
Urban, adjacent to metro, %	6.90%	6.90%	6.90%	6.90%	6.90%	6.90%
Urban, nonadjacent to metro, %	4.20%	4.20%	4.20%	4.10%	4.10%	4.10%
Rural, %	0.40%	0.40%	0.40%	0.40%	0.40%	0.40%
Hospice ownership						
For-profit, %	49.80%	49.70%	49.70%	49.60%	49.60%	49.30%
Non-profit, %	48.40%	48.40%	48.40%	48.50%	48.50%	48.80%
Government-owned, %	1.90%	1.90%	1.90%	1.90%	1.90%	1.90%
Freestanding, %	79.10%	79.20%	79.10%	79.10%	79.10%	79.00%

Abbreviations: ADRD = Alzheimer's Disease and Related Dementias; MA = Medicare Advantage; SD = standard deviation

[a] Exclusions are cumulative across columns.

Appendix Table 3. List of ICD-9 and ICD-10 codes[a] used to identify ADRD

ICD-9		ICD-10	
Code	**Description**	**Code**	
331.0	Alzheimer's disease	G30.9	Alzheimer's disease, unspecified
		G30.0	Alzheimer's disease with early onset
		G30.1	Alzheimer's diseas3 with late onset
		G30.8	Other Alzheimer's disease
331.1	Frontotemporal dementia	G31.0	
331.11	Pick's disease	G31.01	Pick's disease
331.19	Other frontotemporal dementia	G31.09	Other frontotemporal dementia
331.2	Senile degeneration of the brain	G31.1	Senile degeneration of brain, not elsewhere classified
331.7	Cerebral degeneration in diseases classified elsewhere	G94	Other disorders of brain in diseases classified elsewhere
331.82	Dementia with Lewy bodies	G31.83	Dementia with Lewy bodies
290.0	Senile dementia, uncomplicated	F03 .90	Unspecified dementia, without behavioral disturbance
290.1	Presenile dementia (brain syndrome with presenile dementia)		
290.10	Presenile dementia, uncomplicated		
290.11	Presenile dementia, with delirium		
290.12	Presenile dementia, with delusional features		
290.13	Presenile dementia, with depressive features		
290.20	Senile dementia, with delusional features		
290.21	Senile dementia, with depressive features		
290.3	Senile dementia, with delirium		
290.40	Arteriosclerotic dementia, uncomplicated	F01.50	Vascular dementia, without behavioral disturbance
290.41	Arteriosclerotic dementia, with delirium	F01.51	Vascular dementia, with behavioral disturbance
290.42	Arteriosclerotic dementia, with delusional features		
290.43	Arteriosclerotic dementia, with depressive features		
290.8	Other specified senile psychotic conditions	F03.90	Unspecified dementia without behavioral disturbance
290.9	Unspecified senile psychotic condition		
294.0	Amnestic syndrome (Korsakoff's psychosis or syndrome, nonalcoholic)	F04	Amnestic disorder due to known physiological condition
294.1	Dementia in conditions classified elsewhere		

294.10	Dementia in conditions classified elsewhere, without behavioral disturbance	F02.80	Dementia in other diseases classified elsewhere, without behavioral disturbance
294.11	Dementia in conditions classified elsewhere, with behavioral disturbance	F02.81	Dementia in other diseases classified elsewhere, with behavioral disturbance
294.2	Dementia, unspecified		
294.20	Dementia, unspecified, without behavioral disturbance	F03.90	Unspecified dementia, without behavioral disturbance
294.21	Dementia, unspecified, with behavioral disturbance	F03.91	Unspecified dementia, with behavioral disturbance
294.8	Other persistent mental disorders due to conditions classified elsewhere	F06.0	Psychotic disorder with hallucinations due to known physiological condition
		F06.8	Other specified mental disorders due to known physiological condition
797	Senility without mention of psychosis	R41.81	Age-related cognitive decline

[a] This list was constructed by expanding on a previously validated set of ICD-9 indicating ADRD prior to the ICD-9/ICD-10 shift,[190] and identifying their ICD-10 equivalents for use in claims after September 2015

Appendix Table 4. Summary of hospice characteristics

	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
N	2,984	3,027	3,097	3,161	3,272	3,420	3,585	3,655	3,824	3,992	4,127	4,303
Monthly patient census	62.5 (103.1)	72.8 (140.2)	78.5 (154.6)	80.5 (159.8)	83.3 (163.4)	82 (159.5)	78.4 (159.5)	79.7 (169.9)	80.8 (182.2)	82.7 (188.9)	84.4 (200.5)	85.7 (213.3)
Monthly number of care days provided	1303 (2161.4)	1578.4 (3138.3)	1718.5 (3511.7)	1777.1 (3656.2)	1858.5 (3761.1)	1815 (3646.3)	1732.5 (3653.7)	1760.6 (3926.4)	1799.6 (4280)	1839.4 (4439)	1893.6 (4753.9)	1944.3 (5090.7)
RN FTE, mean (SD)	8.8 (17.5)	9.3 (19.3)	9.7 (19.9)	10 (19.9)	10.2 (20.6)	10.4 (20.5)	10.3 (20.1)	10.6 (20.4)	10.5 (20.9)	10.4 (20.5)	10.3 (21.4)	10.1 (20.2)
MD FTE, mean (SD)	1.1 (2.6)	1.1 (2.6)	1.2 (2.6)	1.2 (2.7)	1.5 (11.2)	1.5 (11.3)	1.4 (11)	1.4 (10.8)	1.4 (10.6)	1.2 (2.5)	1.1 (2.1)	1.1 (1.8)
Total employees, mean (SD)	28.3 (61.3)	29.7 (63.7)	30.9 (65.6)	33.3 (90.9)	34.1 (92.7)	34.3 (89.5)	34.2 (89)	33.4 (66.4)	33.3 (69.3)	32.4 (66.9)	31.7 (66.7)	30.3 (62.2)
Level of care												
% RHC, mean (SD)	98.2 (3.6)	98.2 (3)	97.7 (3.9)	97.7 (3.8)	98.2 (4)	98.5 (2.9)	98.5 (3)	98.6 (3.1)	98.6 (3.1)	98.7 (3.7)	98.8 (3.1)	98.9 (3.1)
% CHC, mean (SD)	0.1 (0.5)	0.2 (1.1)	0.2 (0.7)	0.2 (0.9)	0.2 (1.1)	0.2 (0.9)	0.2 (1)	0.2 (0.9)	0.2 (1.2)	0.2 (2.1)	0.2 (1.2)	0.2 (1.3)
% inpatient, mean (SD)	1.3 (3.4)	1.3 (2.7)	1.3 (2.7)	1.3 (2.8)	1.2 (3.7)	1.1 (2.6)	1 (2.7)	1 (2.8)	0.9 (2.7)	0.8 (2.9)	0.7 (2.7)	0.7 (2.6)
% respite, mean (SD)	0.2 (0.4)	0.2 (0.3)	0.2 (0.4)	0.3 (0.4)	0.3 (0.4)	0.3 (0.5)	0.3 (0.4)	0.3 (0.4)	0.3 (0.5)	0.3 (0.5)	0.3 (0.9)	0.3 (0.5)
Place of care												
% home, mean (SD)	61.6 (26.5)	62.1 (26.5)	61.4 (26.6)	61.8 (26)	62.2 (26.1)	62.3 (26.1)	62.7 (25.8)	62.4 (25.8)	62.3 (26.3)	62.1 (26.1)	62.2 (26.3)	62.4 (26.7)
% non-skilled LTC, mean (SD)	24.8 (24.8)	25 (24.7)	26.5 (24.9)	27 (25.1)	27.4 (25.3)	27.8 (25.2)	27.4 (24.8)	27.8 (24.9)	28 (25.1)	28.9 (25.1)	29.3 (25.4)	29.4 (25.6)
% SNF or inpatient, mean (SD)	12.8 (19.4)	12.3 (18.6)	10.8 (16.2)	9.5 (15.5)	9.3 (15.2)	9 (14.5)	8.8 (13.8)	8.6 (14.1)	8.6 (14.4)	7.9 (13.7)	7.6 (13.3)	7.4 (12.9)
Region												
Northeast, %	13.30%	13.40%	13.30%	13.30%	13.00%	12.40%	11.70%	11.30%	10.70%	10.20%	9.70%	9.10%
West, %	18.80%	19.00%	20.00%	20.80%	21%	23.20%	25.10%	27.00%	29.10%	31.40%	33%	34.60%
South, %	42.70%	42.90%	42.60%	42.30%	42.10%	41.60%	41.00%	39.60%	38.50%	37.30%	36.90%	36.20%

Midwest, %	25.20%	25%	24.10%	23.70%	23.60%	22.90%	22%	22.10%	21.70%	21.10%	20.60%	20.10%
Rurality												
Large metro, %	69%	69.60%	71.20%	72.10%	73.00%	76.20%	77.40%	78.40%	79.60%	80.60%	81.10%	82.20%
Urban, metro adj., %	15.70%	15.70%	15%	14.60%	14.20%	12.60%	12%	11.40%	10.90%	11%	10.20%	9%
Urban, non-metro adj., %	12.20%	12.20%	11.40%	11.10%	10.80%	9.70%	9.40%	9%	8.30%	8%	8%	8%
Rural, %	2.80%	2.50%	2.40%	2.20%	2.00%	1.50%	1.50%	1.30%	1.20%	1.10%	1%	0.90%
Hospice ownership												
For-profit, %	54.80%	56.20%	57.80%	59.80%	62%	64.60%	67.00%	68.80%	70.00%	71.00%	73%	74.60%
Non-profit, %	39.10%	38.10%	36.60%	34.90%	33.00%	31%	28.60%	27.10%	26.10%	25.50%	23.80%	22.40%
Government, %	6.10%	5.70%	5.60%	5.30%	5.00%	4.70%	4.40%	4.10%	3.90%	3.50%	3.30%	3.00%
Freestanding, %	64.60%	66.60%	68.60%	70.40%	72.60%	74.90%	77.10%	79.40%	80.70%	82.60%	83.50%	84.50%

Abbreviations: CHC = continuous home care; FTT = failure-to-thrive/debility; LTC = long-term care facility; MD = medical doctor; RHC = routine home care; RN = registered nurse; SD = standard deviation; SNF = skilled nursing home

Appendix Table 5. Differences in the trajectories of percent new monthly enrollees with ADRD, percent monthly patient census with ADRD, and percent care days provided to patients with ADRD coinciding with recent policy changes affecting the Medicare hospice benefit, estimated by fully adjusted models,[a] using alternate ADRD identification and unique hospice episode identification strategies

	ADRD defined using principal and first two contributing diagnoses		**ADRD defined using principal and first three contributing diagnoses**		**Alternate hospice episode identification strategy**	
	Estimate (95% CI)	**p-value**	**Estimate (95% CI)**	**p-value**	**Estimate (95% CI)**	**p-value**
Percent new monthly enrollees with ADRD						
Pre-FTT/debility exclusion slope [b]	0.06 (0.05, 0.07)	<.001	0.06 (0.06, 0.07)	<.001	0.05 (0.04, 0.06)	<.001
Change during FTT/debility exclusion notice	4.02 (3.64, 4.41)	<.001	4.22 (3.83, 4.61)	<.001	3.82 (3.44, 4.20)	<.001
Post-FTT/debility exclusion slope [b]	0.09 (0.05, 0.13)	<.001	0.09 (0.05, 0.13)	<.001	0.09 (0.05, 0.12)	<.001
Change during IMPACT passage	-1.28 (-2, -0.56)	<.001	-1.22 (-1.96, -0.49)	0.001	-1.37 (-2.10, -0.65)	<.001
Change during IMPACT implementation	-2.14 (-2.88, -1.4)	<.001	-2.33 (-3.09, -1.58)	<.001	-2.05 (-2.79, -1.31)	<.001
Post-IMPACT slope [b]	0.18 (0.14, 0.22)	<.001	0.25 (0.21, 0.29)	<.001	0.11 (0.07, 0.15)	<.001
Change during TTP implementation	0.38 (0.01, 0.75)	0.046	0.63 (0.26, 1.01)	0.001	0.21 (-0.15, 0.58)	0.248
Post TTP-slope [b]	0.01 (0, 0.02)	0.014	0.01 (0, 0.02)	0.003	0.01 (0, 0.02)	0.004
Percent monthly patient census with ADRD						
Pre-FTT/debility exclusion slope [b]	0.13 (0.13, 0.13)	<.001	0.14 (0.14, 0.14)	<.001	NA	
Change during FTT/debility exclusion notice	3.19 (2.96, 3.42)	<.001	3.30 (3.06, 3.53)	<.001		
Post-FTT/debility exclusion slope [b]	0.14 (0.12, 0.16)	<.001	0.15 (0.13, 0.18)	<.001		
Change during IMPACT passage	-0.63 (-1.07, -0.19)	0.005	-0.61 (-1.05, -0.16)	0.008		
Change during IMPACT implementation	-1.54 (-1.99, -1.09)	<.001	-1.62 (-2.08, -1.16)	<.001		
Post-IMPACT slope [b]	0.12 (0.10, 0.14)	<.001	0.19 (0.16, 0.21)	<.001		
Change during TTP implementation	-0.15 (-0.37, 0.07)	0.184	0.03 (-0.19, 0.25)	0.81		
Post TTP-slope [b]	0.02 (0.02, 0.03)	<.001	0.03 (0.02, 0.03)	<.001		
Percent monthly care days provided to patients with ADRD						
Pre-FTT/debility exclusion slope [b]	0.15 (0.14, 0.15)	<.001	0.16 (0.15, 0.16)	<.001	NA	
Change during FTT/debility exclusion notice	3.25 (3.00, 3.51)	<.001	3.36 (3.10, 3.61)	<.001		
Post-FTT/debility exclusion slope [b]	0.15 (0.12, 0.17)	<.001	0.16 (0.13, 0.19)	<.001		
Change during IMPACT passage	-0.47 (-0.96, 0.02)	0.058	-0.43 (-0.93, 0.06)	0.084		
Change during IMPACT implementation	-1.47 (-1.96, -0.97)	<.001	-1.53 (-2.03, -1.02)	<.001		
Post-IMPACT slope [b]	0.11 (0.09, 0.14)	<.001	0.18 (0.15, 0.20)	<.001		
Change during TTP implementation	-0.21 (-0.45, 0.03)	0.09	-0.07 (-0.31, 0.17)	0.574		
Post TTP-slope [b]	0.02 (0.02, 0.03)	<.001	0.03 (0.02, 0.03)	<.001		

Abbreviations: ADRD = Alzheimer's Disease and Related Dementias; FTT = failure-to-thrive and debility exclusion as a primary hospice diagnosis; NA = not applicable; TTP = two-tier pay

[a] Adjusted for month indicators, (absorbed) hospice fixed effects + time-varying hospice-level covariates (hospice ownership, total registered nurses, total employees, new enrollee demographic distributions (age, gender, race/ethnicity), percent care days provided at routine home care and continuous home care levels, and percent care days provided in the community/home setting, nonskilled long-term care setting, and skilled nursing home/inpatient setting) + time-varying county-level covariates (population, percent population over age 65 and over age 85, gender and race/ethnicity distribution, number of active physicians, rural-urban setting, percent below poverty level, median household income).

[b] Slope coefficients are direct estimates of the slope during each specified time-period

Appendix Table 6. Differences in the trajectories of percent new monthly enrollees with ADRD, percent monthly patient census with ADRD, and percent care days provided to patients with ADRD coinciding with recent policy changes affecting the Medicare hospice benefit, estimated by fully adjusted models[a] using different subsamples of the data

	Excluding government-owned hospices		Excluding MA enrollees		Subset of hospices in operation between July 2008 and Dec 2019		Limited to data from 2010 and later	
	Estimate (95% CI)	p-value	Estimate (95% CI)	p-value	Estimate (95% CI)	p-value	Estimate (95% CI)	p-value
Percent new monthly enrollees with ADRD								
Pre-FTT/debility exclusion slope [b]	0.05 (0.04, 0.06)	<.001	0.06 (0.05, 0.06)	<.001	0.05 (0.04, 0.05)	<.001	0.06 (0.05, 0.07)	<.001
Change during FTT/debility exclusion notice	3.90 (3.52, 4.28)	<.001	3.93 (3.51, 4.36)	<.001	3.94 (3.56, 4.32)	<.001	3.68 (3.29, 4.06)	<.001
Post-FTT/debility exclusion slope [b]	0.09 (0.06, 0.13)	<.001	0.08 (0.03, 0.12)	<.001	0.07 (0.03, 0.11)	<.001	0.09 (0.06, 0.13)	<.001
Change during IMPACT passage	-1.5 (-2.22, -0.77)	<.001	-1.23 (-2.05, -0.41)	0.003	-1.80 (-2.49, -1.11)	<.001	-1.44 (-2.16, -0.73)	<.001
Change during IMPACT implementation	-1.97 (-2.71, -1.23)	<.001	-2.17 (-3.01, -1.34)	<.001	-1.57 (-2.27, -0.86)	<.001	-1.96 (-2.68, -1.23)	<.001
Post-IMPACT slope [b]	0.12 (0.08, 0.15)	<.001	0.10 (0.06, 0.15)	<.001	0.11 (0.07, 0.14)	<.001	0.11 (0.08, 0.15)	<.001
Change during TTP implementation	0.14 (-0.22, 0.51)	0.447	0.22 (-0.19, 0.64)	0.292	0.48 (0.12, 0.84)	0.009	0.18 (-0.18, 0.54)	0.334
Post TTP-slope [b]	0.01 (0.01, 0.02)	<.001	0.01 (0, 0.02)	0.003	0.02 (0.01, 0.03)	<.001	0.01 (0.01, 0.02)	<.001
Percent monthly patient census with ADRD								
Pre-FTT/debility exclusion slope [b]	0.12 (0.12, 0.13)	<.001	0.12 (0.12, 0.13)	<.001	0.12 (0.11, 0.12)	<.001	0.13 (0.12, 0.14)	<.001
Change during FTT/debility exclusion notice	3.12 (2.89, 3.34)	<.001	2.97 (2.72, 3.23)	<.001	3.01 (2.78, 3.24)	<.001	2.87 (2.64, 3.1)	<.001
Post-FTT/debility exclusion slope [b]	0.13 (0.11, 0.16)	<.001	0.13 (0.1, 0.16)	<.001	0.09 (0.07, 0.12)	<.001	0.13 (0.11, 0.15)	<.001
Change during IMPACT passage	-0.69 (-1.13, -0.25)	0.002	-0.42 (-0.92, 0.08)	0.102	-0.8 (-1.24, -0.36)	<.001	-0.73 (-1.16, -0.3)	<.001
Change during IMPACT implementation	-1.49 (-1.94, -1.05)	<.001	-1.49 (-2.00, -0.97)	<.001	-1.57 (-2.02, -1.12)	<.001	-1.44 (-1.87, -1)	<.001
Post-IMPACT slope [b]	0.05 (0.03, 0.07)	<.001	0.03 (0.01, 0.06)	0.019	0.07 (0.05, 0.1)	<.001	0.05 (0.03, 0.07)	<.001
Change during TTP implementation	-0.29 (-0.51, -0.08)	0.007	-0.34 (-0.59, -0.09)	0.008	-0.13 (-0.36, 0.09)	0.242	-0.34 (-0.54, -0.13)	0.002
Post TTP-slope [b]	0.03 (0.02, 0.03)	<.001	0.02 (0.02, 0.03)	<.001	0.02 (0.02, 0.03)	<.001	0.03 (0.02, 0.03)	<.001
Percent monthly care days provided to patients with ADRD								
Pre-FTT/debility exclusion slope [b]	0.14 (0.13, 0.14)	<.001	0.14 (0.13, 0.14)	<.001	0.13 (0.13, 0.14)	<.001	0.15 (0.14, 0.16)	<.001
Change during FTT/debility exclusion notice	3.22 (2.97, 3.47)	<.001	3.00 (2.72, 3.28)	<.001	3.14 (2.88, 3.4)	<.001	2.89 (2.63, 3.14)	<.001
Post-FTT/debility exclusion slope [b]	0.13 (0.11, 0.16)	<.001	0.14 (0.11, 0.17)	<.001	0.09 (0.06, 0.12)	<.001	0.13 (0.11, 0.16)	<.001
Change during IMPACT passage	-0.48 (-0.96, 0)	0.05	-0.27 (-0.82, 0.29)	0.349	-0.62 (-1.12, -0.12)	0.015	-0.55 (-1.02, -0.08)	0.023
Change during IMPACT implementation	-1.43 (-1.92, -0.94)	<.001	-1.39 (-1.96, -0.82)	<.001	-1.55 (-2.06, -1.04)	<.001	-1.38 (-1.86, -0.9)	<.001
Post-IMPACT slope [b]	0.03 (0.01, 0.06)	0.007	0.02 (-0.01, 0.05)	0.274	0.07 (0.05, 0.1)	<.001	0.04 (0.02, 0.07)	<.001
Change during TTP implementation	-0.30 (-0.53, -0.07)	0.012	-0.37 (-0.65, -0.1)	0.008	-0.23 (-0.47, 0.02)	0.074	-0.38 (-0.61, -0.15)	0.001
Post TTP-slope [b]	0.02 (0.02, 0.03)	<.001	0.02 (0.02, 0.03)	<.001	0.02 (0.02, 0.03)	<.001	0.03 (0.02, 0.03)	<.001

Abbreviations: ADRD = Alzheimer's Disease and Related Dementias; FTT = failure-to-thrive and debility exclusion as a primary hospice diagnosis; TTP = two-tier pay

[a] Adjusted for month indicators, (absorbed) hospice fixed effects + time-varying hospice-level covariates (hospice ownership, total registered nurses, total employees, new enrollee demographic distributions (age, gender, race/ethnicity), percent care days provided at routine home care and continuous home care levels, and percent care days provided in the community/home setting, nonskilled long-term care setting, and skilled nursing home/inpatient setting) + time-varying county-level covariates (population, percent population over age 65 and over age 85, gender and race/ethnicity distribution, number of active physicians, rural-urban setting, percent below poverty level, median household income).
[b] Slope coefficients are direct estimates of the slope during each specified time-period

Appendix Table 7. ICD-9/ICD-10 codes[a] used to identify lung/trachea cancer diagnoses

Code	Description	Code	Description
162.0	Malignant neoplasm of trachea	C33	Malignant neoplasm of trachea
162.2	Malignant neoplasm of main bronchus	C34.0	Malignant neoplasm of main bronchus
		C34.00	Malignant neoplasm of unspecified main bronchus
		C34.01	Malignant neoplasm of right main bronchus
		C34.02	Malignant neoplasm of left main bronchus
162.3	Malignant neoplasm of upper lobe, bronchus or lung	C34.1	Malignant neoplasm of upper lobe, bronchus, or lung
		C34.10	Malignant neoplasm of upper lobe, unspecified bronchus, or lung
		C34.11	Malignant neoplasm of upper lobe, right bronchus, or lung
		C34.12	Malignant neoplasm of upper lobe, left bronchus, or lung
162.4	Malignant neoplasm of middle lobe, bronchus or lung	C34.2	Malignant neoplasm of middle lobe, bronchus or lung
162.5	Malignant neoplasm of lower lobe, bronchus or lung	C34.3	Malignant neoplasm of lower lobe, bronchus or lung
		C34.30	Malignant neoplasm of lower lobe, unspecified bronchus or lung
		C34.31	Malignant neoplasm of lower lobe, left bronchus or lung
		C34.32	Malignant neoplasm of lower lobe, right bronchus or lung
162.8	Malignant neoplasm of other parts of bronchus or lung	C34.8	Malignant neoplasm of overlapping sites of bronchus and lung
		C34.80	Malignant neoplasm of overlapping sites of unspecified bronchus and lung
		C34.81	Malignant neoplasm of overlapping sites of right bronchus and lung
		C34.82	Malignant neoplasm of overlapping sites of left bronchus and lung
162.9	Malignant neoplasm of bronchus and lung, unspecified	C34.9	Malignant neoplasm of unspecified part of bronchus or lung
		C34.90	Malignant neoplasm of unspecified part of unspecified bronchus or lung
		C34.91	Malignant neoplasm of unspecified part of right bronchus or lung
		C34.92	Malignant neoplasm of unspecified part of left bronchus or lung

[a] This list was constructed by expanding on a previously used set of ICD-9 indicating lung/trachea canter prior to the ICD-9/ICD-10 shift,[205] and identifying their ICD-10 equivalents for use in claims after September 2015

Appendix Table 8. Summary of patient characteristics and hospice characteristics across eligible hospice episodes in length-of-stay analyses

	Full sample	**ADRD**	**Lung /trachea cancer**	**Non-profit/ govt-owned**	**For-profit**
N	10,453,025	2,273,272	764,337	5,251,139	5,201,886
		21.75%	7.31%	50.24%	49.76%
Patient characteristics					
Age, mean (SD)	82.7 (8.5)	85.8 (7.2)	76.7 (7.4)	82.6 (8.6)	82.8 (8.5)
Male, %	41.7%	31.3%	51.5%	42.7%	40.6%
Race/ethnicity					
% Non-Hispanic white	87.5%	87.4%	87.7%	90.0%	84.9%
% Non-Hispanic Black	7.9%	8.0%	8.4%	6.3%	9.6%
% Hispanic	1.8%	2.0%	1.0%	1.1%	2.5%
% Other race	2.8%	2.6%	2.9%	2.6%	3.0%
% with any HMO	31.3%	30.0%	32.9%	30.5%	32.1%
% ADRD	21.8%	100.0%	0.0%	18.8%	24.9%
% Lung/trachea cancer	7.5%	0.0%	100.0%	8.7%	6.3%
Hospice/county characteristics					
Ownership					
% For-profit	49.8%	56.8%	41.5%	0.0%	100.0%
% Non-profit	48.3%	41.7%	56.2%	96.2%	0.0%
% Government-owned	1.9%	1.6%	2.3%	3.8%	0.0%
% Freestanding	79.7%	83.1%	76.2%	68.1%	91.4%
Setting rurality					
% Large metro	88.7%	90.1%	87.0%	87.2%	90.2%
% Metropolitan	10.9%	9.6%	12.5%	12.5%	9.3%
% Rural	0.4%	0.4%	0.4%	0.3%	0.5%
Region					
% Northeast	16.0%	15.8%	17.2%	20.0%	12.0%
% West	20.3%	20.9%	17.4%	17.7%	23.0%
% South	39.8%	40.0%	41.3%	34.3%	45.3%
%Midwest	23.9%	23.2%	24.1%	28.1%	19.7%

Abbreviations: ADRD=Alzheimer's disease and related dementias; MA=Medicare Advantage; SD=standard deviation

Appendix Table 9. Estimates of pre-FTT/debility exclusion and post-two tier pay trends in live discharge and length-of-stay[a] in ADRD patients and lung/trachea cancer patients defined using additional ICD codes.

	ADRD - first 3 ICD codes		ADRD - first 4 ICD codes		Lung/trachea cancer - first 3 ICD codes		Lung/trachea cancer - first 4 ICD codes	
	Estimate (95% CI)	**p-value**	**Estimate (95% CI)**	**p-value**	**Estimate (95% CI)**	**p-value**	**Estimate (95% CI)**	**p-value**
Percent live discharge								
pre-policy slope	-0.10 (-0.12, -0.09)	<.001	-0.10 (-0.12, -0.09)	<.001	-0.13 (-0.14, -0.11)	<.001	-0.13 (-0.14, -0.11)	<.001
post-policy slope	-0.03 (-0.04, -0.01)	<.001	-0.03 (-0.04, -0.01)	<.001	-0.03 (-0.05, -0.02)	<.001	-0.03 (-0.05, -0.02)	<.001
pre-policy vs. post-policy p-value		<.001		<.001		<.001		<.001
Mean length-of-stay								
pre-policy slope	0.25 (0.21, 0.28)	<.001	0.25 (0.21, 0.28)	<.001	0.01 (-0.02, 0.03)	0.663	0.01 (-0.02, 0.03)	0.627
post-policy slope	0.57 (0.54, 0.6)	<.001	0.58 (0.55, 0.6)	<.001	0.02 (0, 0.04)	0.061	0.02 (0, 0.05)	0.026
pre-policy vs. post-policy p-value		<.001		<.001		0.301		0.209
Percent stays exceeding 60 days								
pre-policy slope	0.04 (0.02, 0.05)	<.001	0.04 (0.02, 0.05)	<.001	0.01 (-0.01, 0.03)	0.395	0.01 (-0.01, 0.03)	0.379
post-policy slope	0.13 (0.12, 0.14)	<.001	0.13 (0.12, 0.14)	<.001	0.02 (0, 0.03)	0.044	0.02 (0, 0.04)	0.02
pre-policy vs. post-policy p-value		<.001		<.001		0.445		0.327
Percent stays exceeding 180 days								
pre-policy slope	0.04 (0.03, 0.06)	<.001	0.04 (0.03, 0.06)	<.001	0 (-0.01, 0.02)	0.529	0.01 (-0.01, 0.02)	0.45
post-policy slope	0.15 (0.14, 0.16)	<.001	0.15 (0.15, 0.16)	<.001	0.02 (0, 0.03)	0.012	0.02 (0.01, 0.03)	0.004
pre-policy vs. post-policy p-value		<.001		<.001		0.18		0.131

Abbreviations: ADRD=Alzheimer's disease and related dementias; CI=confidence interval; ICD = International Classification of Diseases;

[a] Estimated from models adjusted for month indicators + hospice fixed effects + hospice time-varying covariates (ownership (for-profit vs. non-profit, free-standing vs. affiliated), total registered nurses, total employees, monthly demographic distributions (age, gender, race/ethnicity) of new enrollees, monthly percent of total care days provided at the routine home care level and continuous home care level, and monthly percent of care days provided in the community/home setting, nonskilled long-term care setting, and skilled nursing home/inpatient setting) + county time-varying covariates (total population, percent population aged 65+ and 85+, gender and race/ethnicity distributions, number of active physicians, rural-urban setting, percent below poverty level, median household income)

Appendix Table 10. Slopes in monthly live discharge trends during the period before FTT exclusion notice vs. the period after two-tier pay implementation,[a] by diagnoses, sensitivity analyses.

	Exclude govt-owned hospices		Exclude hospices newly entering or exiting market during observation period		Exclude 2008-2009 discharges		Impute missing discharge status	
	Estimate (95% CI)	**p-value**	**Estimate (95% CI)**	**p-value**	**Estimate (95% CI)**	**p-value**	**Estimate (95% CI)**	**p-value**
All diagnoses								
pre-policy slope	-0.13 (-0.14, -0.12)	<.001	-0.14 (-0.15, -0.13)	<.001	-0.16 (-0.17, -0.15)	<.001	-0.13 (-0.13, -0.12)	<.001
post-policy slope	0 (-0.01, 0.01)	0.713	-0.02 (-0.03, -0.01)	<.001	-0.01 (-0.02, 0)	0.049	-0.01 (-0.02, -0.01)	0.001
pre-policy vs. post-policy p-value		<.001		<.001		<.001		<.001
ADRD								
pre-policy slope	-0.10 (-0.11, -0.09)	<.001	-0.10 (-0.11, -0.08)	<.001	-0.15 (-0.16, -0.13)	<.001	-0.10 (-0.11, -0.08)	<.001
post-policy slope	-0.02 (-0.04, -0.01)	<.001	-0.04 (-0.05, -0.02)	<.001	-0.04 (-0.05, -0.02)	<.001	-0.04 (-0.05, -0.02)	<.001
pre-policy vs. post-policy p-value		<.001		<.001		<.001		<.001
Lung/trachea cancer								
pre-policy slope	-0.12 (-0.14, -0.11)	<.001	-0.14 (-0.15, -0.12)	<.001	-0.16 (-0.18, -0.14)	<.001	-0.13 (-0.14, -0.11)	<.001
post-policy slope	-0.04 (-0.05, -0.02)	<.001	-0.04 (-0.06, -0.03)	<.001	-0.04 (-0.06, -0.02)	<.001	-0.04 (-0.06, -0.03)	<.001
pre-policy vs. post-policy p-value		<.001		<.001		<.001		<.001

Abbreviations: ADRD=Alzheimer's disease and related dementias; CI=confidence interval;

[a] Estimated from models adjusted for month indicators + hospice fixed effects + hospice time-varying covariates (ownership (for-profit vs. non-profit, free-standing vs. affiliated), total registered nurses, total employees, monthly demographic distributions (age, gender, race/ethnicity) of new enrollees, monthly percent of total care days provided at the routine home care level and continuous home care level, and monthly percent of care days provided in the community/home setting, nonskilled long-term care setting, and skilled nursing home/inpatient setting) + county time-varying covariates (total population, percent population aged 65+ and 85+, gender and race/ethnicity distributions, number of active physicians, rural-urban setting, percent below poverty level, median household income)

Appendix Table 11. Slopes in monthly mean length-of-stay during the period before FTT exclusion notice vs. the period after two-tier pay implementation,[a] by diagnoses, sensitivity analyses.

	Exclude govt-owned hospices		Exclude hospices newly entering or exiting market during observation period		Alternate episode identification [b]		Winsorized at 99th pct	
	Estimate (95% CI)	**p-value**	**Estimate (95% CI)**	**p-value**	**Estimate (95% CI)**	**p-value**	**Estimate (95% CI)**	**p-value**
All Diagnoses								
pre-policy slope	0.15 (0.13, 0.16)	<.001	0.15 (0.13, 0.17)	<.001	0.17 (0.15, 0.19)	<.001	0.27 (0.24, 0.29)	<.001
post-policy slope	0.42 (0.4, 0.43)	<.001	0.16 (0.15, 0.17)	<.001	0.44 (0.43, 0.46)	<.001	0.61 (0.59, 0.62)	<.001
pre-policy vs. post-policy p-value		<.001		0.232		<.001		<.001
ADRD								
pre-policy slope	0.29 (0.25, 0.33)	<.001	0.36 (0.32, 0.4)	<.001	0.33 (0.29, 0.37)	<.001	0.54 (0.49, 0.58)	<.001
post-policy slope	0.57 (0.54, 0.6)	<.001	0.20 (0.17, 0.23)	<.001	0.61 (0.58, 0.64)	<.001	0.72 (0.69, 0.76)	<.001
pre-policy vs. post-policy p-value		<.001		<.001		<.001		<.001
Lung/trachea cancer								
pre-policy slope	0.01 (-0.02, 0.03)	0.682	-0.01 (-0.04, 0.01)	0.346	0.01 (-0.02, 0.04)	0.401	0.03 (-0.01, 0.08)	0.122
post-policy slope	0.01 (-0.01, 0.03)	0.481	-0.01 (-0.03, 0.02)	0.622	0.03 (0, 0.05)	0.021	0.05 (0.01, 0.08)	0.013
pre-policy vs. post-policy p-value		0.871		0.627		0.317		0.615

Abbreviations: ADRD=Alzheimer's disease and related dementias; CI=confidence interval;

[a] Estimated from models adjusted for month indicators + hospice fixed effects + hospice time-varying covariates (ownership (for-profit vs. non-profit, free-standing vs. affiliated), total registered nurses, total employees, monthly demographic distributions (age, gender, race/ethnicity) of new enrollees, monthly percent of total care days provided at the routine home care level and continuous home care level, and monthly percent of care days provided in the community/home setting, nonskilled long-term care setting, and skilled nursing home/inpatient setting) + county time-varying covariates (total population, percent population aged 65+ and 85+, gender and race/ethnicity distributions, number of active physicians, rural-urban setting, percent below poverty level, median household income)

[b] New episodes defined as new enrollments, re-enrollments following prior discharge, or new claims following a break exceeding 60 days from the last claim within beneficiary-provide ID pairs.

Appendix Table 12. Slopes in monthly percent stays exceeding 60 days, and monthly percent stays exceeding 180 days during the period before FTT exclusion notice vs. the period after two-tier pay implementation,[a] by diagnoses, sensitivity analyses

	Exclude govt-owned hospices		Exclude hospices newly entering or exiting market during observation period		Alternate episode identification[b]	
	Estimate (95% CI)	**p-value**	**Estimate (95% CI)**	**p-value**	**Estimate (95% CI)**	**p-value**
All Diagnoses						
Percent stays exceeding 60 days						
pre-policy slope	0.05 (0.04, 0.05)	<.001	0.05 (0.04, 0.05)	<.001	0.05 (0.04, 0.06)	<.001
post-policy slope	0.14 (0.14, 0.15)	<.001	0.05 (0.05, 0.06)	<.001	0.15 (0.14, 0.15)	<.001
pre-policy vs. post-policy p-value		<.001		0.046		<.001
Percent stays exceeding 180 days						
pre-policy slope	0.04 (0.04, 0.05)	<.001	0.05 (0.04, 0.05)	<.001	0.06 (0.05, 0.06)	<.001
post-policy slope	0.14 (0.14, 0.15)	<.001	0.06 (0.05, 0.06)	<.001	0.15 (0.15, 0.16)	<.001
pre-policy vs. post-policy p-value		<.001		0.022		<.001
ADRD						
Percent stays exceeding 60 days						
pre-policy slope	0.04 (0.03, 0.06)	<.001	0.06 (0.05, 0.08)	<.001	0.05 (0.04, 0.07)	<.001
post-policy slope	0.13 (0.12, 0.14)	<.001	0.04 (0.03, 0.05)	<.001	0.13 (0.12, 0.14)	<.001
pre-policy vs. post-policy p-value		<.001		0.004		<.001
Percent stays exceeding 180 days						
pre-policy slope	0.06 (0.04, 0.07)	<.001	0.08 (0.06, 0.09)	<.001	0.07 (0.06, 0.08)	<.001
post-policy slope	0.15 (0.14, 0.16)	<.001	0.05 (0.04, 0.06)	<.001	0.16 (0.15, 0.17)	<.001
pre-policy vs. post-policy p-value		<.001		<.001		<.001
Lung/trachea cancer						
Percent stays exceeding 60 days						
pre-policy slope	0.01 (-0.01, 0.03)	0.461	0 (-0.03, 0.02)	0.703	0.01 (-0.01, 0.03)	0.255
post-policy slope	0.01 (-0.01, 0.03)	0.318	0 (-0.02, 0.02)	0.797	0.02 (0, 0.04)	0.032
pre-policy vs. post-policy p-value		0.93		0.582		0.547
Percent stays exceeding 180 days						
pre-policy slope	0.01 (-0.01, 0.02)	0.484	0 (-0.02, 0.01)	0.609	0.01 (0, 0.03)	0.073
post-policy slope	0.01 (0, 0.02)	0.161	0 (-0.02, 0.01)	0.748	0.02 (0.01, 0.03)	<.001
pre-policy vs. post-policy p-value		0.67		0.825		0.287

Abbreviations: ADRD=Alzheimer's disease and related dementias; CI=confidence interval;

[a] Estimated from models adjusted for month indicators + hospice fixed effects + hospice time-varying covariates (ownership (for-profit vs. non-profit, free-standing vs. affiliated), total registered nurses, total employees, monthly demographic distributions (age, gender, race/ethnicity) of new enrollees, monthly percent of total care days provided at the routine home care level and continuous home care level, and monthly percent of care days provided in the community/home setting, nonskilled long-term care setting, and skilled nursing home/inpatient setting) + county time-varying covariates (total population, percent population aged 65+ and 85+, gender and race/ethnicity distributions, number of active physicians, rural-urban setting, percent below poverty level, median household income)

[b] New episodes defined as new enrollments, re-enrollments following prior discharge, or new claims following a break exceeding 60 days from the last claim within beneficiary-provide ID pairs.

Appendix Table 13. Exemplary quotes:[a] IMPACT Act and long-stay audits.

13.i. We just wanted to ensure that all patients were eligible that needed that met the local coverage determination, so you know that the fiscal intermediary or MACs [Medicare Administrative Contractors] have local coverage determinations for each of the diagnostic groups, and we wanted to ensure that all of our patients met eligibility based on the local coverage determination, and really trying to make sure we were documenting more detail than we had originally.
13.ii. I was more – how do you call that – rigid when it comes to admission. Ah, that's why most of my patients right now are short stay patients [……] So admitting short term patient is very expensive because in the first two weeks, the cost is high: visiting nurses, and then chaplain, social worker, on top of that you have the equipment, you have the medication, you have the supplies, so all lumped in the first three days of the admission. And as you move forward, say for example, patient died in four days, all of those costs are already sunk cost, so there's no way for the hospice to recover if it's very short. But it's better that way than Medicare on my back.
13.iii. I mean, definitely before the IMPACT Act, I don't think hospices really knew and understood the local coverage determination, and the guidelines prior to the IMPACT Act, that really kind of brought it out for them in this sense of understanding the expectation, if you will, from the MACs, from Palmetto, from CMS. And so with that, hence the education took place. And so now I think they're a little more reluctant to admit, making sure they're appropriate, and a little more reluctant to keep them on service, again, if they can't 100% determine their appropriateness. So, it to some degree I think has definitely impacted the length of stay for dementia type patients.
13.iv. So I will go on the record saying this is a personal opinion, very outspoken at that. I think it is detrimental first of all, to care to patient care.
13.v. [……] for instance the IMPACT Act you know in terms of, in terms of long length of stay patients. I mean, both nationally and even within [NE state], which is a terribly low utilizer hospice services, you know, we have, we have too little utilization and our stays are very short. So I was never too worried about it because it was never going to affect us.
13.vi. Never rose to my level of reception. But I think we were very conscientious all along about who we enrolled and how we enrolled. And then for, you know, we have long length of stay patients, but you know, we monitor our percentage of long length of stay versus others, and our percentage of long length of days, versus others, routinely from the beginning, because we want to be compliant, and to be able to defend what we're doing, and are those percentages never got out of whack from my point of view.
13.vii. So the policies I think they, they're skewed into really hurting the kind of the smaller organizations that are trying to do the right thing. And the larger ones that, you know, that are kind of trying to game the system take advantage of it for the means of their shareholders and owners. They simply adapt to the changes, fairly quickly. If they're caught with their hands in the cookie jar, they pay their fine. [One case] ended up negotiating a [multi-million] settlement that the hospice paid which they saw as the cost of doing business. So, it does hurt the kind of the smaller hospices, especially the not for-profits that don't have a lot of margin.
13.viii. The other thing that we did was making sure that our utilization review committee was looking at a high length of stay patients through interdisciplinary lens. So having a … you know a social worker, nurse, physician on that task force that could look at these long length of patients say "hey, you know… yes we agree that this patient is still eligible" or "no we need to go back to the team and say, you know, maybe you need to get an albumin on this patient who has dementia, who's weight now has stabilized out.
13.ix. I do wish that the criteria was less strict and being able to go on hospice. I wish that there was more room for human, you know, I wish there was more…You know when you… it's really hard to sit and tell a patient "I know that you're dying. I know that every other piece of the healthcare system has closed their door on you and you were referred to us, but unfortunately, you don't fit into the boxes of dying yet." That's, that's a really hard conversation to have with patients. Yeah, I wish there was a little more leniency in….I was just looking at the heart failure criteria, and one of the qualifications is history of cardiac arrest or resuscitation. Well, not everyone that is dying of heart failure has had a cardiac arrest event. And so, you just like … "well I'm sorry, no one's ever had to do CPR on you, so you don't qualify yet."

13.x. I will also tell you as well as a clinician who teaches prognostication, that of all the diagnosis that come into our doors, [dementia is] the hardest one to prognosticate on. So, whereas you have a patient with metastatic cancer, it's pretty… when you look at functional score and be able to have a pretty solid predictor of death. It is not easy with dementia, and so it takes more skill set. And if you look at some of the, like, LCD guidelines that were established in 1998 or so, which were really based on a consensus panel of providers, there was really no good evidence that supported the use of the FAST scale in dementia. It was neither a sensitive or a specific tool. In other words, there were many people who died of dementia who didn't meet the FAST 7C criteria, and those who did meet the FAST 7C criteria, only 40% died in that time period. And that's still what the OIG when they do their audits, that's one of the main tools that they look at. I know this because I've been involved in some of these legal reviews [……] like 78% of the patients who die of dementia do not fall under the LCD category of having a FAST score of 7C and the other criteria.
13.xi. And I think it was, again defensive and fear based, because the uncertainty of, you know how these evaluations were going to play out, you know, not just within our organization but nationally. And so we were much more hesitant to take on people who did not fit squarely into hospice eligibility categories. So as a clinician, I kind of look at it as three tiers. One, you know, you meet verbatim hospice eligibility criteria, it's documented, no issues whatsoever. The second one is, you may not squarely meet eligibility but you're pretty close and there's a constellation of other factors that, you know you're dying, you know, your life expect six months or less, I'm 90% confident that, you know, nobody would question that. The third category is, look as a clinician with some experience this patient is going to be dead in six months. They may not have any big smoking gun diagnosis, but their trajectory of decline, my clinical experience, you know, it's just… I would offer they'll be dead within six months ergo they meet hospice eligibility criteria. So the second and third categories were almost negated from our care paradigm out of fear, you know. Unless you fit squarely into that almost verbatim, we hit the pause button, we put you on palliative if that's what you're interested in, you know, care for you. But we didn't want to roll the dice, too much at stake, you know.
13.xii. don't think it… so much on the admission. I think we were pretty good on that, I think it probably led us to discharge more quickly, more appropriately, you know maybe when we would've held on to someone, watch them a little longer. It probably put a little more scrutiny on that. So, yeah, so I said …yeah so I said… I don't think it so affected the admission process, but probably did you know, make it a little bit more… I'd say we were a little bit more stringent and very cautious and making sure we were discharging appropriately.
13.xiii. And then as the time went on, It became really discouraging to have to say a patient no longer fit in the terminal status box because they're not declining enough, even though there is no more treatment options for them, their diagnosis cannot be cured, they are still going to die from this diagnosis or disease, and because they're not tightening their belt on another loop or their, their pain regimen hasn't had to increase, now we have to discharge them.
13.xiv. I would agree with that because again, the COPD and CHF, [dementia patients] can look like they're hospice appropriate for almost like the last five years of their lives, honestly. They can have these ups and downs. And so you admit them to hospice and then they stabilize and you get their meds cleaned up, you get them managed, and then they improve and then you have to discharge them from hospice.
13.xv. So, so we had a lady on hospice who we kept benchmarking who had dementia, who could not do any of those things and hardly hold her own head up, but she could speak six or more words. And so we kept not qualifying her, and not qualifying. She couldn't do any of her ADLs. Her family was taking care of her. She was bedridden, she was incontinent for years and years. And because she could say six words in a row, she kept not qualifying. And we ended up admitting her after she developed an infection and she was on hospice for like three or four days, and her family ended up giving us a horrible satisfaction survey. Not because of the care they received, but because of the nightmare it was to get her on hospice.

13.xvi. We had a patient on hospice that had congestive heart failure[……] And this patient's symptoms were pretty status quo, but our home health aide was in there, providing all of the hygiene care, helping do the showers because their spouse couldn't. The social worker was helping them come to terms with this; they had a really large family and they were all pretty emotional about the dying process. And the chaplain was in, called making sure that that their spiritual needs met. The social work, and the chaplain, and the home health aide were by far the most important roles in that home. The nurses were going in, symptoms weren't changing at all, and because of that fear of those audits of long length of stays, and saying he's not using any more pain medication, his weight stayed the same, his appetite has stayed the same, we're going to have to live discharge, and our team was, really really split on that. And so by live discharging a patient, we told that family "He's not dying." And we kind of gave them a bunch of false hope that, because he wasn't declining clinically, he was going to make it. And so all the work that had been done with the anticipatory grief, and the chaplain, and then all of a sudden we're pulling aides out, so then they're having to figure out how to do those services without us, it kind of took away all of that. To the family it was like, "Oh, he's getting better. He's graduating off hospice, he's getting better." So we discharged, they were really, really upset at us, our team here at the office was really divided. And that next week is aneurysm ruptured and died immediately in front of his grandchildren. And they were completely shocked, like you said that he didn't need to be on hospice, or that he didn't qualify for hospice. And so I think what they didn't realize by making that law, was when you discharge a patient because they're not dying quick enough to fit all of the Medicare boxes, it gives the patient false hope that they're actually not dying.
13.xvii. And the patients' families get angry. I mean, "how dare you say my dad's going to live longer than six months?" And they're upset, they're losing a major resource with their families. So they're really very upset, and angry, and what can you do, and the hospice has to deal with that. And so, where they're mad at Palmetto, but they're taking it out on the hospice, so it does make it very difficult, and of course you do have those patients, "I'll show you. You discharge me and I'll die tomorrow kind of thing." And that happens. But I'm not a nurse, but I've done this quite a while. And it's not an exact science. Sure on certain types of cancer, heart, those type of things, yeah, they've got it down pretty good. But the term I've heard a lot, a lot of times is, this patient has the dwindles. Basically they're slowly declining, and there's not one major thing that's causing that, but several things are combined are doing that. And it makes it very difficult very upsetting to the families. And that's the part, that's hard to deal with. You say, "Well, the government makes me do it", or whatever, which is a cop out, and they don't understand. "I've been getting great care, I love my nurse, I love people coming and taking care, and all of a sudden you're gonna take that away from me," and they feel violated at that point.
13.xviii. That's when we started palliative care. So we had a repository of extended length of stay patients, primarily dementia, who still met hospice eligibility criteria, but were on service for an exorbitant amount of time, and certainly would raise red flags. So the palliative care program was created to offload those patients from hospice to protect us from, you know, scrutiny, and potential misinterpretation of guidelines by this independent organization, and ZPICs [Zone Program Integrity Contractors] and fines. So we started a whole new program as a repository for these patients so we can continue to care for them. And then as they approach actual, you know, I don't want to say actively dying, but much, much closer to end of life, if they so choose, we could transition back to hospice level of care.
13.xix. So yes we've had long stay patients, but really what the impact of [the IMPACT Act], was our documentation [……] We've always done a good job with our eligibility and bring in patients that were eligible and you know discharging live at appropriate intervals. So that to me was not the issue the issue was, how do we document, to make sure that we're, we're not going to send up you know flares to the regulatory agencies.
13.xx. There's certain language that tips them off to the good or the bad, and in a very legitimate manner. It's, okay, these are the words and this is a language you need to use to justify, in their eyes, continuation of care beyond a certain length of stay. [……] and then as a physician, right, to help non-physicians understand the physiologic trajectory, how to articulate that through documentation, so it's very clear that even though, let's say, you know, hospice patient looks quote unquote stable and we haven't seen any significant decline, he has a progressive irreversible fatal disease that physiologically is still progressing, even though, you know he hasn't visually changed last two weeks. You know, how to document all of that in an ongoing manner that tells the story and the narrative of physiologic decline, that's, that's been a huge focus over the last couple of years.

13.xxi. There has been a lot of education and when I was still director, we were working with our staff to use more objective terminology, to use measurements, and also to document accentuating the negative. You know, to always accentuate that the patient was still having pain or, you know, infuse use more adjectives and descriptors and objective numbers when possible. Like to quantify how many hours the patient is able to be out of the bed, or to quantify what proportion of meals they're eating, or to use mid upper arm circumference measurements or whatever there might be. So yes, that has that was an also an impact of the IMPACT Act… was to make everybody look more at their documentation and to improve it.
13.xxii. It is an added layer of burden on the agency to ensure that every patient documentation is appropriate, and it takes a lot of time to do that…and that additional staff that basically … you've got somebody sitting reviewing notes all the time rather, than being one that is out in the field, actually helping patients.
13.xxiii. if there's no real need from a therapeutic reason to draw lab work, why should you poke somebody? I mean that's that feels almost criminal, you know it feels abusive. But if you have to obtain some lab work to help justify that they qualify for this benefit, I mean I think most families are okay with it, but it doesn't feel good from a hospice staff standpoint, because they know, again, you're just trying to qualify them for hospice when you could look at the person and go " This person has a six month prognosis," You know they've lost weight or whatever it might be, but it's like you're … you can't use general debility or failure to thrive. So you got to come up with something.
13.xxiv. I have, for example, a hearing on Thursday, in front of administrative law judge for long length of stay patients. All seven patients are being criticized for not being eligible, on the basis of their Alzheimer's disease. And the documentation - the reality is that the documentation is solid. They all have relevant comorbidities by the LCDs and by every other criteria. It looks like they're going to die within the next few months, of this audit month. And so, we will simply point out the documentation is there we're not sure what you're looking at, but the documentation for eligibility for Alzheimer's disease is documented there. And that's what I find in so many of the audits, whether it's with their automated or they've got high school graduates that are doing – and I don't mean to be pejorative, I'm sure it's probably not that – but they give back idiotic responses on their on their audits. In some cases they're cutting and pasting from other patients and it doesn't match the patient under review.
13.xxv. but I think it's also important to acknowledge what our organization has done really to hold that independent review organization accountable, because they are neither clinicians, and it is a for-profit motivated organization that sits independent to CMS, so they get a cut of whatever they collect, and it's not randomized as they state it is. It is certainly directed to find extended length of stay, and we've proven this over and over again in front of administrative law judges. So I think I need to state that it doesn't – I don't want to say it's not legit, but the motivation is not evaluating what the patient care level is like. It is for-profit, you know.
13.xxvi. You know, it makes us nervous, it makes us nervous to know that we kind of always have someone watching us. We have somebody keep an eye on our length of stays, but meanwhile knowing that even though it's slow and steady, we're still making progress in that patient's life.
13.xxvii. You know, this 180 days and six month prognosis, there's been a lot of discussion because our patients don't actually – they're not on a time clock. And so for those patients that were fortunate enough to get to have for six months, that are showing decline, it's a struggle for agencies because they're concerned that the government's going to look at them, and put an audit in place when these patients are absolutely appropriate, they just are taking longer to die than the normal. So that's a complaint, and I hear that everywhere because we want patients to get the advantage of hospice, and when they come on and they die within three days, they don't get it.

[a] Quotes were minimally edited for clarity. Text in square brackets [ ] indicate edited text for purposes of de-identification or clarification [……] indicate omitted text, and … indicates natural pauses in the conversation.

Appendix Table 14. Exemplary quotes:[a] Two-tier payment

14.i. That front loaded a lot of the payment [……] shifting that to the front end, I mean, I think – I felt like it was the right thing to do. Because a lot of the efforts is in that first month or so, where a lot of effort, and then it kind of settles down. So financially shifting that money into that first 60 days and having that two tiered system, I think made sense to me. [……] This hospice probably [had] a neutral sort of thing from a financial standpoint.
14.ii. the smaller agencies were greatly impacted by that. And because most of their length of stay, even if it is under the 180, it is still over 60. So, the majority of their patients are lasting more than 60. So they are negatively impacted by that. And they don't necessarily understand why [……] I mean intuitively it doesn't make sense to them if they're census this is rising, why their revenue is dropping.
14.iii. I don't think they were particularly affected by it. Length of stay is so short that, you know, most of them probably saw a small benefit from the fact that the first 60 days being paid at a higher rate, because medium length of stay is only 17 days in [NE state], you know, that's well under the 60. So you know if some agency took a hit because of the overabundance of their long term patients, you know, that's their issue, and they ought to deal with it. But by and large, I think most of our agencies benefited a little from the 60 day boost in in payment.
14.iv. Did it have a financial impact? Absolutely, it did. It had, I'm trying to remember, 12 million, 16 million impact on our bottom line? [……]. But it didn't change anything at the bedside, right? We didn't change how we thought about patient care, how our marketers looked at patient care. None of that changed. Again, our philosophy is always the same. If somebody is eligible, doesn't matter what their length of stay is or the length of stay trajectory is, we take care of them because they're eligible because they're entitled to the Medicare benefit, and we very strongly believe anybody who is entitled to the benefit because of their prognosis, we should try to support them on hospice.
14.v. I don't hear the providers being concerned about the switch in rates after 60 days. I hope they're not discharging. You know, again, I think the ones that participate with our organization wouldn't be the ones who would discharge after 60 days, but I heard that was a concern nationally.

[a] Quotes were minimally edited for clarity. Text in square brackets [ ] indicate edited text for purposes of de-identification or clarification [……] indicate omitted text, and … indicates natural pauses in the conversation.

Appendix Table 15. Exemplary quotes:[a] Policy motivators and appropriateness

15.i. I mean, when Medicare has to start paying millions and billions more than what they were before then, you know, that's what they do they get their nose in the business and figure out how they can control it because they don't want to have cost, out of control. They're going to blame everybody else and that's just how they get things done. You know, it's to be expected, [in] health care it's to be expected. Unfortunately, they never make anything easier. They make everything harder, every single time.
15.ii. With the patients who are likely to die, and if they are, then I don't know why the federal government should want to whittle down the expenses, particularly since, if they're not in hospice, they're probably getting some other kind of benefit under Medicare, and they can't have both. So the federal government is actually saving money when they elect hospice, evens out in the long term, so they tend to look at things in terms of silos, you know, just hospice or just home health or just hospital, and they don't compare the overall savings that hospice patients offer even if they do elect on the early side. So I think the paradox is, everybody in healthcare is trying to decrease total cost of care. But people are doing it the wrong way. If you're trying to shorten hospice length of stay, the numbers prove the economics of hospice, it costs a hell of a lot less than you know, third line chemotherapy, which is zero sum game and they're going to die. And it doesn't improve their quality-of-life, or how long they live. So absolutely, it hurts patient care. It hurts the opportunity to care. And it jeopardizes the integrity of hospice organization that don't have a large economic runway.
15.iii. you know, originally you know back in 83, 84 when the thing was developed. And then it was back in I think in the late 80s or 90s they were thinking of extending it to a year. There was a there was discussion and so forth to extend it to a year prognosis, but then because of fiscal restraints, Congress couldn't. And then because of fiscal restraints, that never happened, and because of our dysfunctional, our traditional healthcare system, it never happened. But you know, I think (1) it's been clearly shown in multiple studies that it reduces the overall cost, you know, in the big picture. Not maybe the immediate cost but surely the overall cost. And hospice clearly impacts on the quality of care to the individual, and the quality-of-life to the family and caregivers. I mean especially in dementia patients. To give them some degree of respite or relief by having the aids come in and, just for a couple hours and assisting a few times a week or more. You know, to having access. But you know how hard it is now to communicate with your physician. I mean, you call up and you either get told to go to an urgent care go to, you know. And to having immediate access to a physician or nurse practitioner or an RN on a phone call, and not uncommonly to go out and to assess them, really reduces the number of hospitalizations, which are costly. So, yeah, I think the big picture, it would be really advantageous to enhance the hospice benefit to a longer period of time.
15.iv. You know, I get on and I read the OIG [Office of Inspector General, U.S. Department of Health and Human Services] reports. I know that that behavior does happen. I think it's probably more rare than given, you know, than the field. I went to the NHPCO convention in Florida, and a lot of it was on compliance. I know those things do happen and, unfortunately, people dwell on the ones that get caught. I think that most hospices operate with good intention.
15.v. And again, those are more the for-profit folks. So I do see that trend, that the for-profit hospices tend to hang on to patients longer, or maybe it's that they're not evaluating them upon admission as closely as maybe they should be, which is a little concerning. But I think they're just trying to kind of quick get in there and get that patient admitted. There is a lot of competition in [Midwest state], especially in the urban areas, you could find as many as 20 or 30 hospices in [Midwest cities 1, 2, and 3]. And so every referral means a lot to those hospices, as you can imagine.
15.vi. So, money got wrapped around it, and wrapped into it. Before that it was just a straight up philosophy of care, a unique philosophical approach to someone's care at end of life, right? That's what it was. And then money became involved in it, so everybody could access the service. So that changed.
15.vii. you know, there was a lot of love about hospice, and now because of these for-profit players, and the stories we've seen in the media, now there's this tainted view of "really, is hospice really doing what they say they're going to do?" So it's unfortunate. There's not the same trust. So before it was trust in the whole death and dying thing, "do I really need that and when do I need that?" And now you add on the mistrust of the services and the provider.

15.viii. we are lower than average on our dementia facility patients. We don't get those referrals. The for-profits come in and get a lot of those. So that's a small part of our population. We get more of the really sick people, the cancer patients and the more expensive ones.
15.ix. it saddens me to read issues, like in the… the payment advisory committees report every spring about the… that hospices have an average, I don't know what it was…a 14% profit margin or something like that. And the number of for-profit companies coming into hospice, you know, that just feels wrong. And I mean… I shouldn't say that I know there are good for-profits, but you shouldn't go into hospice trying to make money because how you make money is by lowering your labor costs and doing fewer visits, you know, and I don't think that serves patients and families well.
15.x. Well, I mean, so in general, the very elementary answer is "boy creates a lot of paperwork and pain in the you know what, and prevents us from giving good care." But that's a pretty… you know, the sad reality is that fraud exists in this world, right? And we're what we're focusing on is, is limited financial resources, you know, largely from CMS, and CMS wants to know that they have a healthy return on their investment, and they're not being defrauded. So you know, on my best days, I'm able to say, "Yeah, I don't like a lot of these policies, and I don't like the work we have to do to stay compliant with these policies. But they're necessary and it's a statement of our relevance," You know, we're consuming enough of the federal budget that it's relevant.
15.xi. As you as you read the literature, certainly being a not for-profit is not inherently virtuous, and a for-profit is not inherently evil, but it does seem to break down that way a lot in the hospice industry. And I think that incentivizing some of that behavior, I think is a good thing. I wish there were more audits.
15.xii. The quality and compliance department is larger than my provider department. Yeah, we have more people there than I have physicians.
15.xiii. Well it's requiring more staff time, no question, at a time when, when the nursing shortage is very severe. And again, you know, the audits are justified I mean if… if there were regularities and in terms of practice, but you know a variation from the norm doesn't necessarily mean illegal, fraudulent practice. It may just be a difference in the population that you're serving for example, or shortage of staff, and to be able to you know go face to face with patients, and determine eligibility for a benefit periods. There's a lot of factors, and a simple looking at the numbers it's not always going to reveal the truth of the issue. So again if they were more likely to … to work on enforcement of the bad players rather than, you know, trying to make… force everybody to go through the audit and regulatory process so frequently, I think we'd all be better off.
15.xiv. Boy, you know, I would say, as an adult, I feel like we get rules put into place when someone didn't follow the rule. And I feel like this, you know – and I read this studies about fraudulent agencies and, and how they were cherry picking and having long lengths of stays and why this Act became into play. And unfortunately, when people choose to do the wrong thing, it affects all of us. And so I think that all those specific agencies, I feel like should be targeted and an audited and that's why we have CMS surveys and audits. I feel like there should be discipline for saying like "these were the rules and you didn't follow them." But what really ends up happening is like "these are the rules and you didn't follow them, and therefore we're going to punish every other agency in the nation because of it, and we're going to make the rules way more strict." And what occurs by doing that is it, is it takes away care from patients. And so it's, it's like a little bit of a knee jerk reaction to say, "oh, somebody found some holes in our system, and poked those holes. And now we're going to make changes for everyone."
15.xv. I think right now we're under more scrutiny than we've ever been [……] I think it's a little overboard. But in some ways I like it for some other more disrespectable hospices. People that are not performing well. I like the idea that there's a group watching, making sure that everybody's playing by the rules. Even though I'll be honest with you, I think the disrespectable ones do things that are disrespectable, and they're going to get away with the audit anyway.
15.xvi. The government is doing it all wrong. Medicare's doing all wrong. Because, adding more stringent measure to document, and to write out things does not deter corruption, or fraud. Say for example, here in our state [West state], particularly [county], those agencies who are there, and where their only goal is not to serve the patient but to make money, additional documentation will not work because, hey, they can give you the best documentation, ever.
15.xvii. And the other thing that I think is really challenging with dementia patients is that I truly believe that hospice changes the trajectory of the illness. So when you provide that support, you see that patients

actually do better. And there was many years ago by Jean Kutner from the University of Colorado, who looked at you know, what happened when people were discharged from hospice, and there was, you know, a significant mortality rate, when they were discharged. And I think that speaks to the fact that when you have a team of people providing good pain and symptom control, good psychosocial and spiritual support, support not only for the patient but the family unit, the ability to have inpatient unit care or respite care for the family, it actually can change the trajectory of an illness. [……] I'm going to say that there are certain studies that have come out in the cancer literature, [……] when you control symptoms people live longer, up to five months longer. And, you know, [the] study on palliative care and people with lung cancer, which showed as a secondary outcome increase longevity. So I truly believe that because people get this level of care that's so impactful, that it actually can change the trajectory of their illness. And there are other studies in some of the other diagnosis that have also pointed to that.
15.xviii. CMS somehow thinks that they can affect change simply by changing how they have dollars flow, and that's not going to make a difference because the guys who want to play badly will continue to do so, they'll find ways to do it.
15.xix. A: It's had a huge negative effect because it's made hospice staff… it just … it's been such a blow to morale. I mean it doesn't feel good to discharge somebody from hospice, not because really anything with the patient changed, but because you're paranoid that they haven't declined quickly enough, and you can't quantify it. So it's really had a negative impact on morale. And, you know, it's just a burden on hospice staff to always have to quantify and chart negatively. It is difficult. It's difficult to carry around that mindset. I personally am an optimistic person, and to always have to look at the words you use. I mean, it's suggested to hospice staff different phrasing for ways to describe the same situation, but it's all in the semantics and using the language to paint the picture to make the patient look worse.

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Appendix Table 16. Exemplary quotes:[a] Alternative end-of-life models

16.i. I believe that there needs to be a complete revamping of the hospice process, we are operating under the same guidelines that came out in, the law was put into action and 1982. We're so we're closing another 40 year anniversary of it, and other than, you know, some of these policies around the edges, and a minor tweak and the reimbursement by using the U shaped curve model. We're doing the same thing under the same direction that we did 40 years ago, life has changed in 40 years, technology has changed in 40 years. And our understanding of disease has changed in 40 years, and I really believe that that that we need to be looking at an overhaul of the Medicare hospice benefit and really revamping that to be a need based program for people that have terminal illness, as opposed to a prognostically related program.
16.ii. I tend to think that, again, I think that that the regulations as they look are fairly reasonable I think we can defend ourselves appropriately on them. And the goal of preventing fraud is laudable. So, I think that they would do better devoting less time to trying to root out fraud, and just expanding the criteria. Yeah, I think that that would be a much better use of resources, because I don't necessarily think there's anything wrong with offering hospice to a dementia patient who's got a prognosis of 12 months, except that it's not really legal, but from all other standpoints, it's a good idea so. You know it's fraud I suppose to do it, but I don't know that is particularly unethical to do it so. Again I would rather see their efforts at trying to say what makes sense for these patients, and let's do a longer window on them, rather than saying we're going to keep the window really strict and then try to beat up anybody who goes beyond that.
16.iii. I think the initial development of hospice eligibility was created on an incomplete foundation of understanding of, I don't want to say physiology, but the inevitability of life, right? It's artificial almost, and it negates choice. So if as an individual, I don't want to follow the path of an escalation of clinical intervention, which is the linear algorithm by which, you know, hospital systems and the world of medicine operate, it's doing more to a disease or disability. Outside of hospice, I have no choice other than to follow that model if I want any sort of quote unquote health care, right?
16.iv. I can tell you immediately what patients need in the midst of a terminal illness you know one by one. I can always tell you that the necessarily the prognosis I mean I've been doing this [for decades], and I don't think I'm any better prognosticating than I was when I started, because every person is different, and to base your entire system on a prognostication, which is inherently flawed, I think, is a problem.If they just said, you know, if you look at the LCD, forget the six month prognosis. If I got someone with Alzheimer's disease and stage four non healing wounds, you know, and aspiration issues and things like that, they need services. I don't care if they don't live for two months or for two years. They need services and we need to provide them to them. And I can go down the list with any diagnosis, you can talk about COPD or ALS or heart disease, folks that have a specific burden about their illness that require our need our services are going to die as a result of that deserve to have our services. I don't care when they're going to die.
16.v. And what I don't like about this entire Act whatsoever, is Medicare says, “In order to have a hospice program, you have to have these four elements, you have to have a nurse, you have to have a social worker, you have to have a chaplain, you have to have a doctor. without those four things you don't get to have a hospice program, it's required.” And then on the flip side of it they’re saying, “aside from the clinical aspect, it doesn't matter.” And so, that long length of stay is specifically related to whether their vital signs are changing, and whether they're increasing on their pain management. It doesn't matter if they're struggling emotionally, or spiritually. And so it's kind of like a double edged sword where Medicare says it matters so much that you can’t even have a program without it, yet when it comes to a long length of stay it actually doesn't matter. [……] All the time we're making so much ground emotionally, we’ve reconnected them with their children, they've accepted the Lord etc. etc. It doesn't matter. It doesn't matter to that law. All they look at is how many days this patient has been on. And, if they're losing weight and if they're dying in an appropriate timeframe for Medicare.
16.vi. But the whole point of, you know, of disincentivizing long stays is to limit access, and they're trying to limit access of patients who maybe … you know their hospices are taking advantage of the system and so forth. But there has to be another way, there has to be other ways. In fact, I think more access to hospice. Again, not necessarily with a with a concurrent care model, you know, where patients are continuing to get disease directed care as well. But for patients who want a quote unquote hospice

plan of care, you know, patients who, who don't want to go back to the hospital, who want, you know, intensive supportive and palliative care in the home.
16.vii. I think it's really meeting the patients where they're at. And if that means that a particular patient can benefit from that longer length of stay, then it makes sense to be able to provide that care to that patient. Ultimately these patients are going to die, you know they're not going to live for years and years and years. Might be two or three years, but if they provide… or get excellent care for the last two or three years of their life, then I think that's a win, and CMS honestly that is a win. So there's some imbalance, I believe, when they're not looking at true outcomes of the patient.
16.viii. And those are the patients that suffer with chronic illnesses for years before they decide to elect hospice. And so, you know, being, being in home health as well, is like we're missing them. We're missing that gap of people, they're either on home health because they're wanting to get better, or they're on hospice because they're dying, but there's nothing really in between…in between them. So, I guess if I had my ideal world, it would be that all of us were given the opportunity to offer palliative care.
16.ix. And, and there are so many other benefits of hospice that these people are losing out on, with the spiritual care and the social work care that the families need as well as the patient, that these patients that have to wait – cancer patients, the kidney patients – that have to wait until the very end to get on hospice. They lose out a lot of the benefits that makes hospice, part of what it is … you know, mainly what it is besides just the nursing care. I mean, you can bring in a nurse at the house to do what some of our hospice nursing can do. But the whole team approach of hospice, and all the different disciplines that hospice offers for the patients, to have to lose out on that until just the last week or two of their life is, is a shame.
16.x. Improving palliative care home access would be good, because there's really no set reimbursement system for home palliative care. And a lot of these long stay patients are probably home palliative care, but that distinction we make between hospice and palliative care here in the United States is artificial, it's only due to compensation and reimbursement, and the structure of our delivery system. They should be one service provider along a continuum that increases as needs increase and then goes way before death. So we, you know, we're talking a lot of artificial things here that are imposed by our, our healthcare system that aren't real. I mean, hospice and palliative care, it's really only a financial distinction. So it would be nice if we had one service.
16.xi. Well I mean I think that the hospice model is a smart model, is a good model. Um, the issue is the, you know, the restrictions to access [……] I look askance at the projects to encourage concurrent care, because I think that ends up being hospice light. I don't think they get that they really get the full range of palliative interventions. If there's somebody who's still, you know, pursuing the chemotherapy or what have you, you know, there's a disconnect between what we can offer sort of both medically and psych-emotionally when somebody is pursuing that kind of a plan of care, versus when somebody, you know, desires a plan of care that is sort of what traditionally hospice. So that said, it bothers me that that's the way this has been moving in terms of, you know, expanding end of life care options, has been this concurrent care model. What I think would make a lot more sense is that base it on, you know, on plan of care rather than prognosis, you know. Non- hospice palliative care is ostensibly based on need, although more often on availability, but ostensibly based on need rather than prognosis. And I think that that allowing patients to pursue the plan of care that they desire, regardless of prognosis, which may or may not mean hospice would be a more appropriate approach.

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