

The Hospice Algorithm: Capitalizing on Death and Dying

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Abstract

There is extensive literature on the significance of financial incentives in the Hospice Medicare Benefit (HMB) and the growth of proprietary ownership of hospices in the United States. A literature review indicates a paucity of information on hospice nurses' perceptions of the impact of the HMB's financial structure on care planning and delivery decisions. This article presents background on the topic and an initial, exploratory study to address the literature gap, based on interviews of a convenience sample of 48 hospice nurses from 6 different hospices between December 1, 2018, and January 31, 2020, in the New York City metropolitan area. Six themes emerged from the interviews: finances are the guiding principle in care planning and service delivery decisions; appropriate patient selection allows hospices to maximize profit by maximizing length of stay (LOS) and minimizing service utilization; balancing patient care needs, cost, and LOS is a challenge; live discharge decisions save money, but can compromise care; the Interdisciplinary Team (IDT) is where most major decisions are made regarding patient care and finances; and money drives patient care decisions, regardless of ownership type.

Keywords

medicare, nurses, hospice, Hospice Medicare benefit; end of life care, palliative care

Introduction

The purpose of the study presented in this article is to address a gap in the existing literature on studies of hospice nurses' perceptions of the impact of the Hospice Medicare Benefit's (HMB) financial structure on care planning and delivery decision-making.

Establishing Context: The Hospice Medicare Benefit (HMB)

The HMB was not included in the original Medicare program in the 1960s. The HMB was created in 1983 as part of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA) and was made permanent in 1983.^{1–3} Enrollment in the HMB is optional to Medicare beneficiaries. If a beneficiary elects to enroll in HMB, they agree to forgo traditional Medicare coverage for their terminal illness and related conditions. Traditional Medicare continues coverage for items and services that are unrelated to the terminal illness and related conditions. Currently, once a beneficiary enrolls, they must be certified as eligible for an initial period of 90 days based on certification by both a hospice physician and their attending physician as having a prognosis of 6 months or less to live if the illness runs its normal course. If the prognosis remains, the hospice physician can recertify the patient for a second 90-day period and, thereafter, for an unlimited number of 60-day periods. The TEFRA legislation limited the

total coverage to 210 days of hospice care, but 1989 to 1997 legislation removed the 210-day limit (p. 345).³ Once enrolled, a beneficiary also may opt out into traditional Medicare.

Once eligible, the beneficiary may receive a broad array of services designed to provide symptom management and palliative care during the end-of-life (EOL) period. The services include: nursing; physician services; counseling and social work; hospice/home health aides and homemakers; short-term inpatient respite care; drugs and biologicals for symptom control; supplies; home medical equipment; physical, speech, and occupational therapy; bereavement services for the patient's family; and such other services deemed by the hospice as appropriate for palliation and symptom management.⁴ Services are delivered in the beneficiary's place of residence, which may be their home, a skilled nursing facility (SNF), an assisted living facility (ALF), hospital, or a hospice facility. Each beneficiary's care must be under a plan of care which is developed and maintained by an Interdisciplinary Team (IDT), or Interdisciplinary Group (IDG). The team must include at least a hospice physician, registered nurse, social worker, and pastoral counselor (or

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other counselor) and may include other practitioners on either an ongoing or case-by-case basis. There may be one or more teams in a hospice and there is no required frequency of meeting requirements in the Medicare Hospice Conditions of Participation.⁴

The HMB payment model is a risk-based, home-based managed care model which is based on the assumption that it would be a less costly alternative to the conventional Medicare EOL care, which was primarily inpatient hospital care.^{5,6} It includes 4 levels of care, each with a national daily base rate established annually by Medicare and adjusted by geographic location. Once the hospice designates the type of day by level, they bill and receive Medicare payment for the day, regardless of the type and extent of services (if any) rendered on that day. The 4 levels are: Routine Home Care (RHC), which accounted for 98% of all HMB days in 2019 (p. 313).² General Inpatient Care (GIC), which is provided in a facility short-term for symptoms that cannot be managed in another setting; Continuous Home Care (CHC), which is for short-term in-home crises and involves 8 or more hours of care per day, most of which is nursing; and Inpatient Respite Care (IRC), which is care in a facility for a maximum of 5 days in order to give respite to the informal caregiver.

RHC was paid at a single per diem rate until 2016, when Medicare switched to a 2-tier RHC system: a higher rate for the first 60 days (\$199/day in 2021) and lower rate for days 61 and beyond (\$157/day in 2021). Medicare also added payments for up to 4 hours of registered nurse and social worker visits in the last 7 days for patients receiving RHC (at \$60/hour in 2021 (pp. 314, 341-344)).² As of federal fiscal year 2021, Medicare pays \$1046/day for GIP, \$461 for IRC, and \$60/hour for CHC (p. 314).²

The payment system also has 2 caps or limitations, on payments. If either cap is exceeded, it results in an overpayment or payback by the hospice to Medicare. One is the inpatient care day cap which limits the number of inpatient care days a hospice can provide to 20% of its total Medicare patient days (p. 315).² Medicare Payment Assistance Commission (MedPAC) reports the inpatient cap is rarely exceeded.² The second is the aggregate cap, which is a limit on the total Medicare payments a hospice may receive. The aggregate cap amount is set annually by the Center for Medicare and Medicaid Services (CMMS). The aggregate cap is computed by multiplying the per patient cap amount (\$30,684 in 2021) by the total number of Medicare beneficiaries served by the hospice. In 2018, estimated 16% of all hospices (742) exceeded the cap for an estimated average overpayment of \$334,000 per hospice or over \$250 million (pp. 315, 324).²

HMB has grown substantially since being made permanent in 1986. According to MedPAC (p. 313),² in 2019 there were 4840 hospices, more than 1.6 million HMB beneficiaries at a cost of nearly \$21 billion. This compares to the year 2000 when there were only 2300 hospices, 530,000 HMB beneficiaries, and the government spent \$2.9 billion (Abt

Associates, 2013; Government Accountability Office, 2000). Proprietary agencies have grown as a percentage of all HMB providers during these periods. In 1992, proprietaries represented 13% of all Medicare-certified hospices; in 2000, they represented 33%; in 2009% to 53%; in 2023% to 62%; and in 2019, they represented 71%.^{1,2,5,7,8} The proprietary ownership growth in the HMB program indicates the financial incentives of the HMB appear successful in attracting proprietary companies, both chain and non-chain proprietaries. The profit-making attractiveness of the HMB is further validated by the overall profit margins in Medicare hospice and particularly the proprietary hospice profit margins, which always have been higher. For example, in 2008 the overall HMB hospice profit margin rate was 5%, but for-profit hospices had a 10% profit margin.⁷ In 2019, profit margins across all categories of Medicare hospices had increased to 12.4%, driven largely by for-profit hospice margins of 19% (p. 334).^{2,8} Across all Medicare provider categories, the HMB overall profit margin and proprietary hospice margin were second to only Medicare home health and Medicare proprietary home health agencies, respectively (pp. 232, 236, 243-244).⁹

Literature Review

The extensive government data on the relationship between the HMB financial structure and proprietary ownership and profit margins in Medicare-certified hospices prompted a literature review on the impact of these trends on hospice nurses' decision-making. Hospice nurses were selected because of their role and responsibilities in Medicare hospice. Hospice nurses represent the highest percentage of paid full time equivalent (FTE) clinical staff in hospices¹¹; are responsible for supervision of hospice aides, who represent the second highest percentage of paid FTE clinical staff in hospices^{10,11}; are required by Medicare hospice regulations to make an initial assessment visit within 48 hours after the election of hospice and, as part of the IDT, must complete a comprehensive patient assessment within 5 days of the benefit election.¹²

The literature review used CINAHL, PubMed, Medline, Cochrane Library, Campbell Collaboration, PsycINFO, Sociological Abstracts, and Social Science Abstracts databases with a search period of January 1, 1965, through September 30, 2018, followed by an updated search after the study was conducted covering October 1, 2018, through December 31, 2021. Multiple keywords were used in the search: Hospice Medicare Benefit; hospice nursing; proprietary hospice ownership; financial influences on hospice care; financial influences on hospice nurses; and financial factors in hospice care. The search yielded multiple studies on related topics, a sampling of which included: hospice proprietary ownership growth and profitability^{13,14}; hospice proprietary ownership versus non-profit ownership impact on quality of care¹⁵⁻¹⁷; stress and burnout factors on hospice

nurses and other hospice workers¹⁸⁻²¹; and the impact of hospice care on family caregivers,²²⁻²⁴ but no studies specifically on hospice nurses' perceptions of the impact of the Hospice Medicare Benefit's financial structure on care planning and delivery decision-making.

While there were no studies specifically on hospice nurses, there were 2 studies by Livne^{25,26} that dealt with other hospice or hospital palliative care workers. Livne²⁵ conducted a 1 year "ethnographic fieldwork" study of a non-profit hospice in California (p. 893). The ethnographic work included interviews with a variety of hospice staff which he described as hospice liaison (to hospitals), office worker, manager, nurse, and social worker but did not specify how many persons he interviewed in each category. He combined his interviews and observations with "historical analysis" (p. 893). His overall conclusion was that scarcity of resources, often due to financial reasons, itself became a moral value to adopt "the view that 'less is better' and the wish to save patients from overtreatment (p. 888)." Livne argues there was a convergence between the "financial interests to limit spending on end-of-life care and imbuing financial constraints with positive moral meanings (p. 889)."

Livne expanded his 2014 work in a 2019 book based on his ethnographic study of palliative care in 3 hospitals in the same metropolitan area in California—one a public, safety net hospital; one a for-profit hospital; and third being an academic or university medical center. He based his work on observations and interviews at the 3 hospitals. He "conducted a total of 80 interviews with physicians, nurses, social workers, chaplains, and some administrative staff" (p. 268) with most lasting 50 to 70 minutes. He concludes that the practices he observed did not vary significantly across the hospitals. He noted the intersection between morality and what he termed economization. "For one thing, the palliative care interpretation is very convincing. Its advocates and practitioners have established palliative care not only as a *beneficial* way to care for the dying, but also as a *moral* one (p. 271)."

Livne makes it clear his purpose is "neither to praise nor condemn palliative care" (p. 272), but to analyze it. In his analysis he observes the same synergy between morality and economization that he observed in his earlier hospice study. He calls this the "new economy of dying" and asserts "Most defining of this economy is the judgment that, when it comes to the end of life, less is oftentimes better (p. 12)." His interviews and observations show, in his view, the cloaking of financial interests with a moral purpose. He also reviewed the archive of a hospital ethics committee and concluded that "Physicians were the ones who promoted more economized dying processes, and the main challenge in end-of-life care became bringing patients and families to embrace less invasive care and consent to economizing dying (p. 25)." In reviewing his interview notes and observations, he also focuses on what he calls "taming," which means taming hopes of various patients and families "that did not correspond with what clinicians and hospitals deemed feasible (p.

25)." He asserts none of the taming practices used by palliative care clinicians "*imposed* any agenda on patients. They rather aimed to moderate wishes that did not resonate with the economized pattern of dying (p. 25)."

While the literature review revealed no studies directly on point with my interest in hospice nurse perceptions, the themes in Livne's work provided an entry to my research question and design. I was interested in whether his themes resonated in a different setting (hospice versus hospital-based palliative care), among a different set of stakeholders (hospice nurses), and with a different payer source (HMB vs traditional Medicare and commercial insurance).

The present study is designed to address this gap in the existing literature regarding the topic. The study presents the results of an exploratory, qualitative design using semi-structured interviews of 48 hospice nurses from 6 different hospices in the New York City metropolitan area between December 1, 2018, and January 31, 2020. The location and selection of the interviewees were based on a snowball convenience sampling process based on convenience of access to the researcher. The nurses came about equally from proprietary hospices (25 nurses; 52% of total) and non-profit hospices (23 nurses; 48% of total). The study uses interviews to probe nurses' perceptions of the impact of the Hospice Medicare Benefit's (HMB) financial structure on care planning and service delivery decision-making.

Methods

Data were collected through interviews of 48 home care nurses, selected from the New York City metropolitan area between December 1, 2018, and January 31, 2020. The nurses came about equally from proprietary hospices (25 nurses; 52% of total) and non-profit hospices (23 nurses; 48% of total). All interviews were conducted in person using an interview guide to help standardize the data collection. The time of interviews was pre-COVID-19. As a result, no questions were included regarding the impact of COVID-19. In-person interviews were conducted at locations convenient to participants and off-site from where they worked. The study was self-funded by the researcher and therefore not subject to any IRB approval. However, all study participants received and signed informed consents written in compliance with federal regulations and all participants were assured of anonymity and confidentiality.

The study uses a grounded theory approach.²⁸ Grounded theory is the research methodology of choice because it was developed for interpreting qualitative data in the absence of a pre-existing theory. Open coding was used to fracture the data to "identify some categories, their properties, and dimensional locations (p. 97)."²⁷ The coding and classification generated a list of 237 codes. Code and category labels were created, systematically sorted, compared, and contrasted until they were complete, with no new codes or categories produced and all data accounted for. Through axial

Table 1. Hospice Nurse Participant Demographic Characteristics.

Characteristic	Number	Percent
Gender		
Male	2	5
Female	46	95
Race/Ethnicity		
Caucasian, Non-Hispanic	39	81
Hispanic	3	6
African American	3	6
Asian American	2	4
Other	1	3
Age range		
> 55	2	5
45-55	39	81
36-44	4	8
25-35	3	6
Years as a hospice nurse		
> 10	4	8
6-10	5	9
1-5	38	80
< 1	1	3
Average patient caseload		
26-30	4	8.5
20-25	4	8.5
< 20	40	83

coding, multiple phenomena were identified from the connected categories and subcategories. These phenomena included the structure of the HMB decision-making framework, hospice nurse perceptions of HMB and its financial structure, hospice nurse perceptions of their hospice's use of the HMB financial framework in impacting care planning and delivery decisions, and hospice nurse perceptions of impacts of their hospice's emphasis on HMB finances as a guiding framework in meeting hospice patient and caregiver needs. Finally, using selective coding, a "story line" was identified and a "story" written that integrated the axial coding phenomena.²⁷ The story that emerged was the influence of HMB's financial incentives for profit on hospice nurse decision-making and the limitations on meeting hospice patient and caregiver needs.

In keeping with the grounded theory approach, the data analysis and interpretation were facilitated by analytical and self-reflective memo writing, which helped move empirical data to a conceptual level; expanded and refined the data and codes; developed core categories and interrelationships; and integrated the experiences, interactions, and processes embodied in the data.²⁸ All initial abstraction, analysis, and interpretation were done by the author of this article. After the initial process, all abstraction, analysis, and interpretations were reviewed by 2 additional experienced qualitative researchers, each of whom had a doctoral degree in social work and more than 15 years' experience doing government-funded qualitative

research on health care. Any differences were discussed by the 2 external reviewers and the author to reach final decisions used for the study results. All analyses were done using ATLAS.ti software.

Limited demographic data was collected from study participants using a short survey. The results appear in Table 1. Overall, the hospice nurses were 45 to 55 years old (81%); female (95%); Caucasian non-Hispanic (81%); had 1 to 5 years of hospice experience (80%); and had an average caseload of less than 20 patients (83%). The nurses came about equally from proprietary hospices (25 nurses; 52% of total) and non-profit hospices (23 nurses; 48% of total). Statistical analysis of the demographic variables' impact on study outcomes was not done due to the qualitative nature of the study. The study was based on one geographic area and on interviews only of nurses based on a convenience sample. As such, it adds insight to the issue, but the findings cannot be generalized beyond the study setting and interviewees.

Results

Six themes emerged from the interviews, which are detailed below with supporting quotes. Overall, the results reflected hospice nurses' perceptions that the HMB, as administered in their hospices, placed an undue emphasis on finances as a determinant of care decisions, resulting in adverse consequences in terms of unmet patient and caregiver needs. The themes follow.

Finances Are the Guiding Principle in Care Planning and Delivery Decisions: "It was almost as though they gave us a formula, like an algorithm, to guide our decisions to maximize financial benefit to the hospice, not care to the patient." Nurse TR

All nurses interviewed agreed with the sentiment of Nurse TR that their hospice, regardless of ownership type, placed a primary emphasis on financial consequences in care planning and delivery decisions. Nurse TR was the most explicit, stating further:

I get it. I understand. They [the hospice owners, investors and executives] want to make money. It's okay to make money. It's the American way, even in healthcare, but not at the expense of care. That's what's happening here, where I work. It is out of balance. Care needs to be a greater priority. It's becoming less of a priority. Nurse TR

Other nurses expressed similar views:

They [the hospice owners and executives] do everything but give us the profile of the ideal patient. They are not shy about it. It starts with how they recruit patients, mainly the non-Cancer patients; what type of care and how much we should give' how long the patient should stay on care; and what to do if the patient gets too costly. They do not put it in writing, but we are trained,

oriented, supervised and managed with these points explicitly conveyed. We understand they want us to see less [care] as better care; that limited, or no treatment is the right and compassionate way in hospice. It's not always true but it suits their interests and a lot of us nurses and others but into it. Nurse LT

I agree. We agree told in meetings, trainings, and supervision about the ideal patient and the ideal patient is ideal from a financial perspective, not ideal on how best to meet the patient's needs. Don't get me wrong. I am not saying the owners and managers don't care about patients. I think many of them do. They just get so caught up in the finances that they lose focus. Nurse SS

Absolutely, finances are the central focus. I had a patient profile in my mind, and it is a profile of what makes the patient good for our hospice's financial wellbeing. That's it. We do patient profiling. I hate it and battle it, but it is part of our reality. Nurse TZ

I guess they see it as a business and the more I learn, the more it seems Medicare created it [the HMB] with financial incentives to make profit while they supposedly will save Medicare costs for hospital care at the end of life. That is my impression. I don't see how we are saving the government money, but the owners and the people they hire to run our hospice sure spend a lot of time on strategies to make profit for our hospice. Nurse BW

The nurses' perceptions are supported by the previously cited MedPAC data on high profit margins for both for-profit and non-profit owned hospices, more so for for-profits, and the growth in for-profit hospice ownership.³

Appropriate Patient Selection Allows Hospices to Maximize Profit by Maximizing Length of Stay (LOS) and Minimizing Service Utilization

Nurses interviewed repeatedly emphasized the need to have profitable patients by having long lengths of stay (LOS) with low service costs. MedPAC data shows most HMB spending in 2019 was for patients exceeding 180 days LOS (p. 323)³ and that for-profit hospices had the highest length of stay (112 days) (p.322).³In 2018, MedPAC found that Medicare profit margins increased as LOS increased and, more specifically, profit margins increased as share of stays exceeded 180 days (p. 335).³ MedPAC data (p. 336)³ also shows that in 2018 hospice profits increased as their share of patients in skilled nursing facilities (SNFs) and assisted living facilities (ALFs) increased. In multiple reports, MedPAC has found patients in both SNF and ALF settings are less costly to hospices because of the responsibilities of the SNF and ALF for service provision (p. 335).³

Our hospice spends a lot of time and money targeting certain doctors and hospitals, and especially any nursing home or assisted living facility in our area because they can give us what they call 'Good prospects.' These are patients that meet the

Medicare hospice eligibility criteria, and can generate a lot of recertifications, which means a long LOS. The nursing home and assisted living patients also require less staff because these places cover a lot of the care and when we go it saves us travel time and mileage costs because we do not go there as often as if they were in their own homes. Nurse PF

That is why we have so many nursing home patients. Everyone loves it. We [nurses, social workers, home health aides] like it because we visit less frequently and have less responsibility. We get there and in one place we can see multiple patients in a short period. It is the nursing homes that deal with the 24/7 needs and crises, not us. Our owners and managers like it because most of these patients cost less and have long lengths of stay compared to our other at-home patients. We get paid but the nursing home really is responsible for most of the care that we'd otherwise do if the person were in their own home. Nurse SH

It's not as though some of these patients with a long length of stay don't need care. It's just that the level of care they require can be dealt with for longer periods of time with less costly caregivers like home health aides or even volunteers or spiritual care providers, or even leaning more on the family or other informal caregivers. I have a lot of patients with Dementia or Parkinson's Disease. They fluctuate in their level of care needs but often have long stretches without needing a nurse or even a social worker, which are our most costly staff. So, yes, we can just keep them on in what's like more custodial care, I guess, than medical care. These are easier patients for us, and I guess they are more profitable, so our marketing people really recruit a lot of them. Nurse TO

The non-cancer patients are less costly and have longer lengths of stay. You can see that in our caseload. We have had a steady increase in our non-cancer caseload, what we call our neuro patients, ones with neurological disorders like Dementia or Parkinson's Disease as their primary diagnosis. The same is true for patients with heart and respiratory primary diagnoses. These [non-cancer] patients now are more than 50% of our caseload. Our marketing people target these patients by going to certain doctors of ALFs or SNFs that have units that specialize in these conditions. Nurse RS

MedPAC data supports Nurse RS' observations, noting that the average length of stay nationally for patients through 2018 who were "neurological" was 360 days compared to 131 days for cancer patients in above-cap hospices and 228 for neurological compared to 74 for cancer patients in below-cap hospices. The data also showed patients with COPD and heart/circulatory as primary conditions had significantly higher LOS than cancer patients in both above and below-cap hospices (p.335).³

Balancing Patient Care Needs, Cost, and Length of Stay is A Challenge

All nurses agreed that balancing patient and caregiver needs with cost and length of stay considerations was a challenge, though nurses varied in the degree of the challenge.

It's not that straightforward. It gets complicated. Sometimes you get a patient with a long length of stay but then their care needs spike and you can't say 'no' to their care needs. Our finance people don't like when that happens, but it does, and we [nurses] deal with it. I think they [the finance people] have enough of what they call 'good patents'—ones with limited needs and long stays—that it works out for the hospice financially, but I still feel the pressure to limit care. I do what I need to do professionally to meet the patient needs but others [nurses] aren't as strong and limit care more than I think is appropriate. I can be a real stressor. Nurse DL

It can be a real challenge balancing care and cost. We all know what the ideal patient looks like for the hospice's financial wellbeing. We are tuned into it and respect it, but you can't always walk that tightrope between care and cost. As nurses we know people at the end of life need nursing care, even when they've opted for so-called non-treatment under hospice. It is about quality of care and sometimes you need a nurse, not a non-skilled person, if only for consistent, ongoing patient monitoring. Sometimes I have issues with my supervisor's decision or an IDT [Interdisciplinary Team] meeting decision where a patient clearly needs more nursing, but they decide to decrease the frequency of our visits and to substitute one volunteer or clergy or family-based care because of the cost of nursing. It can be very frustrating. Nurse TW

I had one patient; she was the nicest person. She had Parkinson's [Disease]. For most of her first benefit period, she barely required any nursing care, not even social work. I'd say for an easy 60 days we just did maybe one nursing visit a week, a few aide visits, and maybe one social work visit each month. She got great care for her needs and the hospice made good money. You can figure it out. She was on Routine Home Care (RHC) level [of hospice care], so we had to be getting \$200 or so a day. Then, as happens with Parkinson's patients, her care needs spiked. It was no longer mild cognitive issues, but she had a lot more medical needs, most resulting from a fall or two. That happens a lot with these patients and ones with dementia or MS [Multiple Sclerosis]. Her care needs skyrocketed. I want at least nursing in there 3 times a week for a month or so to ensure she was stabilized. Instead, I was approved for two nursing visits a week for two weeks and an increase in [home health] aide visits and volunteer time. I was so disappointed. It can be so difficult balancing the care with the cost. We are there to care and be professional, but we do not have enough power to control the decisions all the time. Nurse JJ

Live Discharge Decisions Save Money, But Can Compromise Care

A live discharge is a discharge from the HMB while the beneficiary is still alive. According to MedPAC, the two major reasons for such discharges are "beneficiary revocation" and hospice-determined "beneficiary not terminally ill," each constituting 6.5% of all live discharges in 2019 when live discharges were 17.4% of all hospice discharges (p. 330).³ A MedPAC commissioned report by Abt Associates found that

both reasons for live discharge increased as hospice providers reached or surpassed the cap, raising concerns about "hospice-encouraged revocations or inappropriate live discharges (p. 331)."³

Sometimes I think they, they administrative people, you know, think it's like a game. I get it. People have options. Medicare allows people to opt in and out of hospice care. That's fair. What isn't fair is when we basically coerce the person or their spouse or significant other to revoke. I've seen that happen with administrative people giving a call and discussing 'issues' with the patient or family member. Sometimes they [the administrative people] try to have us do it. I won't. Then there are situations where we initiate a discharge because we determine the patient is ineligible, that is no longer terminally ill. Yes, that does happen, but in most cases, it is a close call, and I am suspicious of what role finances play in the decision to find the patient is no longer terminally ill. I'm not saying these are rampant practices, but they do occur and, as far as I can determine, these patients often still qualify for and need hospice care. Nurse SN

Sure, here are legitimate live discharges. People decide to opt out for whatever reason. That seems fine. And sometimes people just stabilize, like a miracle, or seem to get so much better that they no longer need care and we see them as no longer terminal. That happens. The doctor always needs to be involved in the 'no longer terminal' live discharges, but it is not always clear and all these decisions go through the interdisciplinary team. I have seen pressure applied to the doctor, and sometimes they give in because it is a close call, so to speak, as many decisions are on prognoses and number of months expected to live. The pressure isn't blatant. These [administrative] people are very sophisticated and subtle about it; some even have medical credentials to bolster their views. What is problematic for me is when it seems our hospice's administrative, or management people are using the live discharge as a safety valve to avoid a [perceived] financial loss on a case. I have seen some where I feel that has been done. It happens more often than I'd like to admit. Nurse WR

I have seen a lot of these live discharge decisions in my 20 years in hospice. They are usually close calls on whether the patient is no longer terminal. I have seen almost equivalent cases where on one we do a live discharge for the patient no longer being terminal and on the other case we keep them on service. In these cases, I have not seen any major clinical difference, so it always makes me wonder if something else is going on, like the need to save or make money. I know that might sound paranoid, but it does make me suspicious. Nurse TL

The Interdisciplinary Team (IDT) Is Where Most Major Decisions Are Made Regarding Patient Care and Finances

The HMB requires that each hospice patient must have a written plan of care established and maintained by an interdisciplinary team (IDT) in consultation with the patient's attending physician.⁴ The IDT is also referred to as an interdisciplinary group (IDG). The team must include a hospice

physician, registered nurse, social worker, and pastoral care or another counselor. There may be additional members of the team. A hospice may have more than one IDT and the frequency of IDT meetings is not specified. The plan of care must identify services to be provided and describe the scope and frequency of services needed to meet the patient's and family's needs, including management of discomfort and symptom relief. As such, the IDT also makes decisions about appropriateness of both the nature and extent of continuing care and appropriateness of discharge.

The IDT is it. That is where our big decisions are made. I've worked at 5 different hospices. The teams meet with different frequency but always timely enough to review all new admissions, ongoing cases, and proposed discharges. Well, that's the way it works in most cases. Some hospices do it better than others some get to all these cases timely while others don't. We nurses make decisions on a day-to-day basis but within the plan of care. If there is a significant change, we act quickly and do what is necessary in our professional opinion, but then it needs to go to the IDT as soon as possible, especially if it is a significant change in the plan of care. Nurse ZL

I really like the IDT concept. I used to work in [Medicare-certified] home care and wish we had it there. It is only required in hospice. However, I have been disillusioned with how it's been used sometimes in the two hospices where I have worked. I understand the need for both clinical and non-clinical input on cases, but the non-clinical role has gone too far in my experience. It is one thing to have non-clinical people like spiritual care and volunteer representatives but not finance and other administrative people. I do not see the point. We are making care decisions. The finance people should not be there. Care should be the basis of the decision and then we figure out how to finance it, not the reverse. In my experience these [non-clinical] people have too much power. They are there to represent the CEO and when they speak it carries a lot of weight, and when they speak their concern is usually about money, not holistic hospice care. Nurse ZD

I always thought the IDT was for people who gave direct care to make decisions on admissions, recertification, discharge readiness and planning, and the plan of care for their patients and other hospice patients. These are the people who know and understand the palliative care context of hospice. That is how it was when I started in hospice many years ago. The care needs were the focus, not so much the finances. Now, the IDT is still the control point for all these decisions, but there are more administrative people, and every care decision immediately gets into a cost discussion. It's almost flipped to where money is the central decision-making factor. I talk to colleagues at other hospices, and they say the same. I don't think it is right. Nurse DS

Money Drives Patient Care Decisions, Regardless of Ownership Type

As noted earlier, the HMB has one set of regulations and one reimbursement structure, which does not vary by ownership type. The reimbursement structure was designed using a risk-based managed care model to incentivize hospice providers to

reduce Medicare end-of-life care costs while at least maintaining the same or an improved quality of care.^{2,3} It was designed to afford the opportunity for hospices to profit. As a result, Medicare-certified hospices have evolved to having the highest profit margins among all Medicare providers. According to MedPAC (p. 334),³ Medicare hospice profits have been steadily increasing with a 2018 profit margin of 12.4% across all hospices. For-profit hospices have outpaced non-profits consistently with a 2018 profit margin of 19%. The profitability has contributed to an increase in for-profit ownership of hospices with 71% of all Medicare-certified hospices in 2019 in the United States are for-profit hospices (p. 317).³ The hospice business has become so lucrative that it has attracted investment by private equity firms.²⁸ Nevertheless, non-profit hospices had a 3.8% profit margin in 2018, the third year in a row since 2016 when non-profit hospices have a positive profit margin above 2% (p. 334).³

All nurses interviewed agreed that making a profit was a primary concern of all hospice owners and administrators, regardless of whether the hospice was for-profit or non-profit.

I have worked in three hospices. One was for-profit and the other two were non-profits. There was nothing different. It was a constant tug of war in each hospice between clinical priorities and financial priorities. The system is set up that way. Medicare has done it. If you want to survive as a business, you need to work within the Medicare framework. Otherwise, you lose. Nurse LT

What's that old saying? "It's not personal; it's business." Well, that's the way these businesses, these hospices, operate. It is business, no doubt about it, but, in this case, it is also personal. Why? Because of the implications for patients and their families. It is the same business, regardless of who owns it. Sure, the for-profit people are even more focused on money, especially if they have investors, but the non-profits need to watch their bottom-line too. So, they all use the same strategies. They all go to the same seminars & conferences, belong to the same trade groups, hire the same consultants, and hire more people with business and finance degrees to run the operation. It is survival of the fittest and money makes the decisions. Nurse TC

It is competitive. It doesn't matter how you are incorporated. I talked to my sister about this. She is a lawyer. She said it is all about business. If you are a non-profit operating in the same [service] area as one or more for-profits, you cannot afford to operate only on empathy and caring principles. You need to be financially solvent, she said. You may not need to make the same level of profit as the for-profits, but you need to make money. That means financial factors will affect a lot of decisions much more than you might otherwise want. Nurse LJ

I heard an economist talk about public policy once. I forget his name. He said the government sets the rules by which we live and that is why government is so important. He went on about the importance of voting and power distribution among monied interests. Now I see what he meant just by observing where I work. Medicare set the rules for this hospice benefit. Congress did it. They basically made it a profit-driven business instead of

a public health service. They made it so you get paid flat rates per day and can lose or make money, based on how you manage your type of patient, their cost and how long they stay on service. That is what you need to balance. There is no point in operating a hospice to lose money. You enter at risk and need to manage that risk so you can survive and make money or help people or both, depending on your motivation. I do not like it. I do not think it is right, but that is the way it is until those rules change.
Nurse MH

Discussion

Despite its limitations, the study does begin to address a gap in the literature on hospice nurses' perceptions of the impact of the Hospice Medicare Benefit's (HMB) financial structure on care planning and delivery decision-making. The nurses' perceptions expose practices that explain much of the MedPAC data on profit margins, proprietary ownership growth, length of stay and service utilization differentials, live discharges, and care burden shift to family and other caregivers of hospice patients. The question now becomes: What are the implications for HMB reform? One reform approach might be to propose elimination of the risk-based, financial incentive approach that has created the imbalance between care and financial considerations in Medicare hospice care planning and service delivery decisions. Such an approach would necessitate either a total shift of Medicare to some form of a universal health care public health model or at least such a shift only for the HMB. Such an analysis is well beyond the scope of this article. As a result, this section will discuss some potential changes within the current risk based HMB framework designed to restore more balance in care planning and service delivery decisions.

MedPAC has acknowledged limitations in the existing HMB financial structure in terms of Medicare spending on end-of-life care but has not focused on existing research of the negative aspects of the financial structure on hospice care for patients and their caregivers. They acknowledge that "Limited quality data are available for hospice providers (p. 310)."³ They further acknowledge that the Medicare "composite measure [of the seven processes of care at hospice admission] is nearly topped out; that is, scores are so high and unvarying that meaningful distinctions and improvement in performance can no longer be made (p. 310)."³ MedPAC also acknowledges research is mixed on whether the HMB has fulfilled original premise, namely that HMB would be less costly than conventional end-of-life care. More specifically, MedPAC cites 2015 research commissioned by MedPAC which "found that while hospice provides savings for some beneficiaries, such as those with cancer, overall, hospice has not reduced net program spending and may have increased net spending because of very long stays among some hospice enrollees (p. 315)."³

Despite these acknowledgments, MedPAC simultaneously rationalizes the existing HMB structure, stating "The

indicators of payment adequacy for hospices—beneficiary access to care, quality of care, provider access to capital, and Medicare payments relative to providers' costs—are positive (p. 339)."³ As a result, MedPAC's 2021 recommendation to Congress was only "to eliminate the update to the 2021 Medicare base payment rates for hospice and wage adjust and reduce the hospice aggregate cap by 20 percent (p. 339)."³ MedPAC (p. 340)³ has projected the proposed cap reduction would have no adverse impact on beneficiary access to care. While the cap adjustment is an important, yet not legislated action, it is only one of multiple policy actions that Congress could initiate to better address the concerns of the nurses in the current study about the imbalance between financial well-being of hospice owners and the end-of-life wellbeing of hospice patients and their caregivers. These policy alternatives seem worthy of greater discussion by policymakers and the hospice community, even given the current additional constraints of the COVID-19 era on healthcare.

The cap reduction proposal itself seems a reasonable approach but requires greater specificity. MedPAC has noted that, "The hospice cap is the only significant fiscal constraint on the growth of program expenditures for hospice care (p. 315)."^{3,6} However, the cap has not constrained program expenditures and in no way has been researched regarding its impact on care. MedPAC's proposal to reduce the cap limit by 20%, seems like a solution to reduce the current 16% of hospices that MedPAC estimated exceeded the cap in 2018, at a total cost of nearly \$250 million (pp. 317, 324).³ These hospices had a profit margin of 22% prior to application of the cap, and 10% after cap application (p. 311).³

The question becomes why do these hospices continue to exceed the cap if they know they must pay back the excess? While MedPAC does not probe this question, several factors seem instructive in answering the question and reforming the cap in addition to merely reducing its level. One factor is that there is no penalty for exceeding the cap. It effectively is a no-interest loan during the year, or longer, for each hospice. Hospices can use that money for cash flow, thus avoiding taking loans or drawing on interest-bearing lines of credit, or to invest in stocks or bonds to generate further income. A penalty is an important reform. The penalty could come in several forms. One would be an actual penalty charge to be paid to Medicare for exceeding the cap. This would be in addition to paying the overpayment amount and any interest thereon. Another penalty approach could be placing a percentage holdback on payments in the following year for all hospices that exceeded caps in the prior year. Both options should be explored. MedPAC has not addressed this issue.

Another approach, separate from or with a new penalty system, could be retroactive interest charges. Under current law governing Medicare overpayments, interest is not applied retroactively for the overpayment period. It only applied if the provider does not repay the overpayment within 30 days of an overpayment demand letter.²⁹

In addition, any interest charge on cap-exceeding hospices should not be allowed as a tax deduction or any other type of tax benefit for the corporate provider. Under current Medicare and federal tax law, if repayment of an overpayment (presumably including any interest charges) is characterized as a repayment, then the provider can claim the amount as a tax deduction on their federal income taxes. However, if it is characterized as a fine or penalty, then it cannot be claimed as a tax deduction.³⁰ This would require a specific legislative provision to ensure the repayment terminology characterization could not be used in situations where Medicare-certified hospices exceed the cap and to reinforce the existing law on no tax deductions eligibility for fines or penalties.

A second reform might be greater restrictions on long length of stay patients. MedPAC noted that “Nearly 60 percent of Medicare hospice spending was for patients with stays exceeding 180 days (p. 323).”³ Part of the reason for such long stays is the open-ended nature of hospice benefit periods. Under the original 1982 legislation creating the HMB, effective in 1983, there were successive benefit periods a Medicare beneficiary could elect, subject to a physician certification of a life expectancy prognosis of 6 months or less to live, with a maximum of 210 days (p. 313).³ The original legislation was amended in 1989 to 1997 to allow a first benefit period of 90 days, a second for period 90 days, and, thereafter, an unlimited number of 60-day periods (pp. 313, 345).³ One possible reform might include a decreased payment rate for all hospice beneficiaries exceeding a 180-day LOS, or maybe even a shorter LOS threshold (pp. 342-343).³ MedPAC (pp. 342-343)³ actually has mentioned, though not made a formal recommendation, for lower payment rates after 180-day. Another reform might be to decrease the second benefit period to either 30 to 60 days, with increased documentation requirements for subsequent approval, including an approval from both the patient’s hospice and attending physician (currently both physicians must certify the initial period, but only the hospice physician for the subsequent benefit periods) and a physician at the Medicare contractor.

A third reform might be to require an automatic Medicare contractor/intermediary review of all live discharge determinations by a hospice which are based on “discharge for cause” or “no longer terminally ill.” These 2 reasons accounted for 40% of all live discharges between 2017 and 2019 (p. 330).³ The logic of such a possible requirement is to limit the unilateral discretion of the hospice to make live discharge decisions which might be based on financial interest as opposed to eligibility requirements. In such a scenario, any hospice-initiated live discharges would be considered only as proposals that would be sent to the Medicare within a specified time-frame prior to actual discharge and could not be implemented without the contractor/intermediary approval.

A separate, but related, potential reform, might be an adjunct benefit for patients either with the potential for long stays or which a hospice feels should receive a live discharge.

In such situations, an external contractor/intermediary medical review would be required, either at a set point in time (possibly after 90 days) or upon the hospice’s preliminary decision to do a live discharge. If approved, the Medicare contractor/intermediary could approve coverage by a separately designed palliative care benefit to support the patient and caregivers. The services could be provided through the hospice or a Medicare-certified home health agency.

A fourth reform, which might more directly address care issues, might be to expand the current Inpatient Care Rate (IRC) period from a total of 5 days to a total of 10 days. The logic of such a reform would be to provide more support in situations where there is significant burden on the informal caregiver.

Limitations

This study is a qualitative, exploratory study. As such it does not address causality and has several limitations including: small sample size; lack of random sampling for sample selection; and lack of a randomized controlled trial experimental design to test specific interventions against a control group. The study also is limited to one geographic area and based on interviews only of hospice nurses and only hospice nurses who were accessed through the researcher’s contacts with hospice nurses. As a qualitative study there also is no quantitative analysis of results by key demographic characteristics such as age, gender, caseload size, years of experience in hospice care, or ownership status of hospices in which the nurses worked.

Conclusion

In the movie *Jerry Maguire*, Cuba Gooding’s character, Rod Tidwell, exhorts Maguire to “Show Me the Money.” Ultimately, Maguire shows Tidwell the money by securing Tidwell a robust professional football contract renewal. We are left with the impression that showing Tidwell the money substantially improves both Tidwell and Maguire’s quality of life. Indeed, the Medicare program has shown hospice owners, particularly proprietary hospice owners, the money. Whether that money, the planned financial incentives of HMB for hospice owners, has improved care for persons at the end of life and their caregivers remains an open question. Both MedPAC and other researchers continue to probe the issue. In the meantime, ground level hospice nurses in this modest study indicate patient and caregiver care often suffer at the expenses of financial considerations. As Nurse TR recounted, “It is out of balance. Care needs to be a greater priority.” There are policy options that might restore that balance. Perhaps it is time the major national hospice associations shift their focus with Congress and the United States Department of Health and Human Services from maintaining or increasing their payment levels to policy changes aimed improving care, even at the expense of financial incentives.

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