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Hospice, Heal Thyself

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DECEMBER 18, 2025 10.1377/forefront.20251210.57249

Hospice in the United States is in trouble, having fallen victim to severe dysfunctions that afflict American healthcare. Dishonest business practices and instances of outright fraud are not hard to find and would seem hard to ignore in the face of multiple federal and state government reports and exposés in print and broadcast media. The vast majority of hospice programs are legitimate and well intentioned, nevertheless, the quality of hospice care is highly variable and unreliable. The professional and trade associations that represent the country's hospice industry have been perfunctory in responding to these problems, largely confining their efforts to writing recommendations to Congress and the Centers for Medicare & Medicaid Services (CMS).

Years of vague program guidelines, insufficient regulations, and lax oversight, combined with ever-more-aggressive pursuit of corporate profits, have resulted in wide variations in hospice staffing, training, clinical protocols, and performance. In the same town, hospice nurse case managers may be responsible for 12 to 14 patients in one program and 16 or 18 patients in another. Differences in caseloads directly affect the frequency and number of visits nurses can make to patients' homes. The same holds true for doctors. As companies cut costs by hiring fewer doctors, home visits by doctors, which were once a mainstay of hospice care, have become unusual. Hospice nurses have described to me their discomfort when their hospice team's physician prescribes opioids, such as morphine and fentanyl, and sedatives, such as Ativan and Haldol, based solely on their recommendations.

To be fair, even middling hospice programs suffice much of the time. Less frequent, but not any less important, are those urgent and irregular moments which reveal critical deficiencies. When a hospice team is insufficiently staffed, practiced, and prepared, those weaknesses can transform symptom crises – which are not rare among dying patients – into far deeper catastrophes. A patient's pain breaks through routine medications, or seizures occur and don't stop. Under the care of a high-functioning hospice team, such problems are rapidly treated and resolved. Without timely and effective responses, patients experience prolonged suffering and their families feel abandoned.

Authentic hospice care has the power to transform dying patients' experiences and their families' lives. We must not lose this level of human caring.

Redefining The Problem Yields Solutions

The deterioration of American hospice care is often cast as the fault of for-profit hospice corporations. That's understandable, but assigning blame based on tax status is not helpful. Here's what's true: For-profits have flourished under Medicare's model of paying a daily rate – currently $224.62 – for routine hospice care. Eighty percent of hospices in the U.S. are for-profit companies which on average yield financial margins of 20.5% annually, compared with 5.8% of non-profit programs. For-profit hospices tend to selectively enroll patients who are likely to live longer and require less complex and less expensive care. In general, they employ fewer nurses and doctors per patient and make fewer home visits. The for-profit programs also score lower on national family caregiver ratings.

All of this seems damning. However, within these group-level quality data, one can find a few high-performing for-profit programs, including some that are investor owned. These positive outliers are evidence that it's possible to turn a profit by providing high quality hospice care. Rather than framing this dilemma as an issue of hospice ownership, it is more useful to see it simply as a matter of good care versus bad care.

Workable solutions to bad care are available. They will require the hospice field itself to own and feel responsible for resolving these problems. Solutions cannot be outsourced to Congress or CMS.

It is long overdue for the national hospice and palliative care professional and trade associations to issue explicit standards for safe and effective hospice programs and practice. Such standards would define the scope of services offered by hospice programs, delineate necessary administrative and clinical processes applicable to case referrals, evaluation and admission, and clinical assessments. They would specify requirements for staffing, minimum qualifications and training, and elaborate the core roles and responsibilities of each clinician discipline within the hospice interdisciplinary team. In addition, program standards would elucidate corresponding structural and administrative capacities necessary for the team to function successfully and maintain staff well-being.

The associations that represent hospice in the United States have never publicly acknowledged their reluctance to publish standards. In my conversations with association executives and elected board members, they typically give one of three justifications. The first is: "We already have standards." This usually refers to the Clinical Practice Guidelines for Quality Palliative Care published by the National Consensus Project (NCP), which are intentionally categorical, qualitative, and aspirational rather than operational. Nor are they specific to hospice programs of care. A second response is: "It's not our job to issue standards." This answer ignores the historical development of the professions for which the delineation and maintenance of standards was a core purpose.

A third rationale offered is that it is not necessary to publish standards because, "The free market will work these problems out." This response is rooted in the economic theory of Nobel laureate Milton Friedman. I never trusted that assertion, but ironically, I have come to depend on it proving true. Unfortunately, at present the market isn't free. Competition is tied up and tangled in unseemly ways. Referrals to hospice from hospitals or physician group practices often turn on whether an attending physician is affiliated with a local hospice company, or whether a program is owned by the hospital or parent health system. Decisions about which hospice programs to include in a preferred provider network of a health insurance plan or healthcare provider corporation are similarly opaque, based on corporate affiliations, financial considerations, and volume discounts.

I believe we must take a new strategic path forward that pivots from fearing capitalism to freeing the market in ways that enable hospice companies to financially thrive if – and only if – they demonstrate reliably good quality. Although existing data sources and measures of access and quality of hospice care are imperfect, they suffice to begin aligning market pressures with improving quality.

This past July, an independent expert panel on which I served issued a report entitled, The Measures That Matter in Hospice Care. Our goal was to highlight specific measures from available public data that can inform health plans' decisions about which hospice programs to include in their networks. These measures included:

- the proportion of patients receiving each of the four levels of hospice care,
- lengths of hospice service,
- the number and timeliness of visits,
- frequencies of burdensome transitions of care,
- ratings of patient and family caregiver experience, and
- percentages of patients discharged from hospice care before their death.

It is quite possible to envision a market where this kind of information directly informs purchasers' and patients' decisions. And when financial success in that market turns on demonstrated quality, the name or tax status of a clinical program's corporate owner becomes irrelevant. The main question in choosing a hospice would become whether the program is good enough to care for someone's mother, or father, or spouse, or child.

Needed: The Leadership Of Our Field's Elected Boards

The field can and should take some big steps toward protecting the public from fraudulent scams and quality shams:

First, national hospice and palliative care professional and trade associations must issue clear and explicit clinical and program standards – both minimum specifications and best practices.

They must also endorse a corresponding set of quality measures that accurately monitor performance.

What is more, these associations should actively promote quality data to the public and oversight agencies, recognizing outstanding hospice programs with “seals of approval” while also highlighting programs which underperform.

Finally, by regularly updating quality measurement methodologies and quality data, they can support better focused and effective actions by state departments of health, auditors, and prosecutors, and the U.S. Department of Health and Human Services, CMS, the Office of the Inspector General, and the Department of Justice.

Renewed Attention

The market would be a lot freer if patients, families, and hospital discharge planners could readily pull up comparative quality data of every hospice program in their region. Imagine the impact on competition for referrals if people could see at a glance how often, on average, a program’s patients are visited by a nurse, by a doctor, by home health or bath aides, along with family satisfaction scores, willingness to recommend ratings, and annual staff satisfaction scores and turnover rates.

This is achievable. Not all categories of meaningful data are currently available; however, existing resources, including Medicare’s Hospice Compare and the National Hospice Locator, display important information relevant to choosing or referring to a hospice program within a given region. Regrettably, at present these sites are underutilized, while hospice referral patterns remain unduly influenced by explicit or informal business relationships. My hope is that with the renewed attention of our field’s elected boards, these and other public-facing sites will be iteratively refined with more and better information about each hospice program’s structure, care processes, and quality outcomes. The professional field and business community of hospice in the United States should accelerate this shift toward quality-based competition by actively promoting relevant quality data to payors, corporate customers, and the public.

This strategy is straightforward, but it will not be easy. Expect the publicly traded and private equity owned corporations to question the legitimacy of published standards and resist making their data transparent. The elected directors of the leading national associations – particularly the American Academy of Hospice and Palliative Medicine, the Hospice & Palliative Nurses Association, and the Social Work Hospice & Palliative Care Network – will need to be courageous and tenacious to overcome that resistance. As stewards of this vital healthcare specialty, it is the responsibility of elected boards to safeguard dying patients and restore the reputational integrity of hospice care in America.

Let’s hope they meet this moment.

Author’s Note

The author is a founding member of the American Academy of Hospice and Palliative Medicine (originally, the American Academy of Hospice Physicians) and served on the Academy's elected board and a year (1997) as its president.