

# Saving health systems and patients from a “Bad Death”

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## Commentary

Many developed and developing nations are in heated discourse about access to affordable health care, systemic inequities in healthcare systems, and unsustainable costs. This essay will focus on Medicare, the United States' public healthcare program for senior citizens, but the principles apply to any nation or healthcare system facing the challenge of a rapidly growing population of aging patients living with oftentimes one or more chronic, progressive medical conditions.

In the United States, there is a metaphorical “tsunami” of baby-boomers enrolling in Medicare, at a rate of 10,000 per day, with an ever-diminishing Medicare trust fund to maintain this entitlement [1]. Medicare covers about 13% of the US population but constitutes about 16% of all healthcare spending. Surprisingly little is ever spoken about the actual distribution of the Medicare budget (approaching \$600 billion US dollars per year), nor the highly disproportionate amount on this cohort of Americans during the last year of life—about 25% of all Medicare expenditures are on the 5% of beneficiaries who die every year. Nor has the value of those expenditures been analyzed or elucidated been in terms of meeting stated patient goals, improving overall health, well-being, and quality of life, or life expectancy of Medicare beneficiaries. Like much else within the fragmented US healthcare system, we are spending far more than can be justified by the outcomes obtained [2].

Perhaps talking about costs of care at the end of life by political figures is perceived as too threatening, dangerous, touchy, or incomprehensible to capture the attention of the electorate. This is both regrettable and counterproductive since there are very real solutions to many of the monumental healthcare economic issues we face—with broad economic, personal financial, and health- and quality-of-life implications—that can be derived from thoughtful analysis. This begins with an understanding of “lessons learned” from the only comprehensive advanced illness managed care program in the United States that has historical financial and quality data—the Medicare Hospice Benefit (MHB).

Let's get started right out of the gate with those factors that made the 1982 legislated MHB so unique in its day. For the first time, Medicare offered an entitlement under Part A for end-of-life care that recognized the limits of the acute care system, and the unique needs of families and patients experiencing far advanced, life-limiting illnesses. It was the first per diem, capitated benefit of its type offered—that is, a full managed care plan for comprehensive end-of-life care, with 4 levels of service, including routine home care, respite care, continuous (crisis) care, and general inpatient care. Importantly, the MHB conditions of participation contain interdisciplinary team and comprehensive service requirements, recognizing not just biomedical needs, but social, emotional, practical and spiritual needs in support of both patient and family. The only major caveat was—and continues to be—a life

expectancy of 6 months or less if the disease runs its usual course. Parenthetically, it needs to be noted that “usual course” has not been, and cannot be, defined for any given individual experiencing a chronic progressive condition—that factor has meaningful implications, which will be discussed when we come to prognostication.

So, with regard to the economics of healthcare in the US as it relates to end-of-life care, what has changed in the last several decades, what has stayed the same, and what lessons can be drawn since the inception of the MHB?

In 1983, 99% of the less than 5000 patients care for by a Medicare Certified hospice program had cancer. Now only about half of the more than one million hospice patients in hospice every year die from cancer. Nevertheless, median life expectancy of hospice patients then, and now, is far less than a month. Overall life expectancy is now 20% longer for Medicare beneficiaries than it was 40 years ago, with ever-increasing prognostic uncertainty due to medical advances, and there has been a 50% increase in the US population over 65 years of age. Nevertheless, the top 3 causes of death have largely gone unchanged with heart disease leading the way, followed by cancer and cerebrovascular disease, and dementing illness is on the rise.

Total healthcare expenditures as a proportion of GDP have just about doubled, from about 10% to 20%. As stated, Medicare expenditures during the last year of life are a quarter of the entire Medicare budget for the approximately 5% of all beneficiaries who die each year, but hospice utilization is only a small fraction (11%) of last year of life Medicare expenditures. That is because 85% of beneficiary days during the last year of life are not spent being care for by a hospice team. Most medical and related healthcare needs are fractionated, with a significant proportion of costs being attributed to repeated hospitalizations. And that's where the most profound opportunities for improving quality and costs of care lie, as we'll see.

Due to inflation, it now costs about \$2.50 to buy what \$1 could 35 years ago, or a 150% change. With that in mind, the per diem MHB reimbursement rate for routine home care has gone up more than 200%. That sounds pretty good, until you factor in that RN incomes have gone up 300% and physician incomes have appreciated 260%. That's good for hospice staff, but hardly proportionate relative to changes in hospice remuneration. Accurate comparative data on pharmaceuticals, medical supplies and equipment are a bit more difficult to acquire, but needless to say, those costs have recently sky rocketed.

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A final financial metric that cannot be overlooked is the relative cost of hospice care versus hospitalization at the end of life. At the inception of the Medicare Hospice Benefit, the charges for a hospice day was 16% of an acute care hospital day; now it is 8%, meaning that the cost—or at least charges—for routine hospitalization has risen disproportionately higher than that for hospice care. For ICU admissions, the disparity is much greater, with current ICU costs per day exceeding 50 times that of a hospice day. In 1983 it was about a fourth of that. So, from a healthcare economics perspective, there have been dramatic changes over the last four decades.

Now let's move on to key clinical factors. With advances in medical care, prognostic uncertainty has only increased, making it more and more difficult to prejudge life expectancy in almost all disease categories. Frailty as a health phenotype among the Medicare population, along with dementing illness, continues to rise as other primary causes of death are delayed, further complicating accuracy of prognosis, and increasing costs of care, in an increasingly large population of older Americans. There is little if any prospective evidentiary science to guide Medicare's local coverage determinations (LCDs) for hospice eligibility applied to a given patient, based on empirically determined sensitivity and specificity factors. In other words, except for patients at the brink of death (showing overt signs and symptoms of actively dying), regardless of leading diagnosis, co-morbidities and associated clinical variables, making predictions about 6 months life expectancy is no better than a coin toss. This unpredictability is further confounded by the influence of hospice care often improving life expectancy due to myriad psychological, social and nursing/medical care factors.

The clinical reality of prognostic uncertainty does not jibe with current interpretation of regulations and implementation of administrative rules around hospice eligibility and payment, in any realistic way. Simply said, biomedical and social determinants involved in predicting population-based life expectancy do not apply on a case by case basis. But an over-emphasis on either withholding or clawing back payments to hospice programs that admit patients who live longer than 6 months has had a chilling effect on timely hospice admissions. Ironically, this has not only hurt patients and their families directly, but this practice has been economically unsound [3].

Most importantly to those living with a chronic progressive and life-limiting condition, when comparing both life expectancy and quality of life with and without hospice care, the hospice paradigm has been highly effective at meeting both key end-outcomes—especially

adherence to patient goals and values—for those who are referred to and receive hospice care in a timely manner (more than a few days to weeks).

In sum, the key lesson learned from the “hospice experiment” on a national scale, as implemented through the MHB, is that the clinical and economic benefits of this coordinated, interdisciplinary model are profound, but they have barely been tapped. Again, with only 15% of current last year of life days being lived under the hospice care model, there is great room for improvement. It has been calculated that for every 1% increase in hospice days for the Medicare beneficiary pool that dies every year, the Medicare trust fund would be \$600 million US dollars richer—and patients and their families would be far better off.

With death as the inevitable outcome, it would only seem wise to work toward defining and normalizing populations requiring advanced illness care along the lines of the hospice model, acknowledging the absurdity of a “6-month prognosis” to qualify for enrollment. Over the last few decades working within this model, we've learned to meet critically ill patient and family needs, and to do so in a highly cost-effective manner, making this package of services a model for more comprehensive, coordinated advanced illness care as part of the continuum of chronic disease management [4,5].

The challenge now is to implement, or at least re-orient policies that create positive incentives for providers and payers to be aligned in service of patient and family best interests. Doing so will provide both timely and useful coordinated preventative, restorative and palliative care that optimize quality days while cost-effectively preventing decompensations that lead to avoidable hospitalization, poor outcomes and squandered resources. Now there's a talking point!

## References

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