

Medicare Advantage and Hospice Care: My Family's Difficult Story

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What is the message? Medicare Advantage plan enrollment now exceeds 50% of the total Medicare beneficiary population. MedPAC estimates that private insurers are now being paid at a higher level than the cost of enrollees within traditional Medicare, increasing total Medicare spending. This essay argues that pressure to reduce that spending is incentivizing Medicare Advantage plans and their contracted providers to favor financial considerations rather than the needs of terminally ill patients and their families.

What is the evidence? A first-person account around the decision to engage hospice care and the actions by providers in the context of a Medicare Advantage plan and a contracted medical group.

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Introduction

My story is a family saga involving Medicare Advantage (MA) and the incentives it might create for providers who influence hospice care for terminally ill individuals. My family's experience

represents the struggles facing a growing number of families due to policy and system-level factors in the current U.S. healthcare environment.

The current number of Medicare Advantage members has risen to 51 percent of total Medicare beneficiaries, with the forecast to reach 60 percent by 2030 (Neuman et al., 2024). It has been argued that many factors support this trend of increasing membership in MA plans, stemming from factors such as better convenience, benefits, and financial protection for beneficiaries as well as aggressive marketing by insurance companies.¹ From a policy perspective, there is concern that MA plans are actually increasing overall Medicare spending as private insurers increase covered MA beneficiaries and are paid at a much higher level (by Medicare) than the cost of equivalent traditional Medicare. This is according to the most recent Medicare Payment Advisory Commission (MedPAC) public meeting.^{1,2} Approximately half of Medicare decedents received hospice care).² Increasing MA enrollment coupled with financial pressures and use of hospice, set an increasingly complex stage for terminally ill patients and their families.

Our Story

Both of my parents were academics at Case Western Reserve University (CWRU.) Dad received his MD in his late 40s after receiving his PhD in his 20s. Mom received her PhD four years after Dad, delayed after caring for me for my first three years. Both had distinguished careers: Mom was the first female department chair at CWRU, and later finished her career at Cleveland State as Associate Dean of Education. They spent 20 wonderful years of retirement in Southern California after 34 years of often brutal winter weather in Cleveland, Ohio. My father's increasing debilitation with Alzheimer's forced my parents to move to Dallas to be closer to me, their only child, in mid-2012.

Dad only survived another nine months after their move. He mercifully suffered what was probably a stroke and passed with some of his cognitive abilities still intact (although he was still convinced he had traveled to the moon). My mother had undergone mitral valve repair surgery and a quadruple bypass in early 2008 back in California. By 2019, at 92, she experienced substantial valve leakage and suffered from advanced heart failure and failing kidneys.

When my parents first moved from California to Dallas, they were able to move into an

independent living facility that was only 1.5 miles from my home. It was a comfortable existence, with a most convenient in-house primary care clinic offering access to both network specialty and hospital care coordinated as part of a Medicare Advantage plan. My parents left their traditional care coverage for this new option. Their increasing age and frailty, coupled with a local provider available by foot, made this an easy decision.

When Covid hit in early March 2020, only one caregiver was allowed access to the residents. I became that caregiver, which proved to be extremely important as Mom's heart ailments led to her continued decline. She began suffering from bouts of severe arrhythmia, which ultimately could not be ameliorated through ablation or medications. Finally, her electro-cardiologist admitted her into our local heart hospital for evaluation.

It took nine days of her inpatient stay for her medical team to sort out her electrical system, which resulted in the implant of a pacemaker. Looking back, that lengthy stay must have severely negatively impacted her individual risk spending metrics in relation to the premiums her Medicare Advantage program was receiving for her care. It would appear that her illness trajectory would present strong incentives to remove her from the MA plan by transitioning her into hospice care

Post-Discharge

Within the first week of my mother's discharge, her primary care physician set up a post-discharge phone call with me. She announced in a clinical but assertive tone that my mother had at most six months to live and that we needed to begin planning for her transition to hospice care. Of course, this was terribly sad news and I shed many tears for what I later learned from our hospice grief counselor was "anticipatory grief."

One night in June, as she continued to decline, my independent mother decided to forgo help from her night aide and fell on the way to the restroom. She suffered a broken wrist and, as can be expected, the cascading of events led to her final passing. Mom passed in July 2021, having lived 13 months rather than the less than the six months predicted by her physician.

As a side note, when my mother fell, her hospice nurse told us that all falls are considered related to the terminal condition. As a result, my mother had to sign an agreement that she

would be financially responsible for all costs incurred related to the orthopedists' services. I also worried about the prospect that she might need surgery and that we would be financially responsible for both professional and facility charges. However, the surgeon felt that her cast was sufficient for her arm to heal. This situation, which undoubtedly occurs often, appears to frequently burden people without necessary means and who may suffer from more debilitating injuries such as fractured hips or legs. This absolute cost shift to the patient felt cruel to us, like the system was "piling on" during one of the most stressful experiences a family, i.e., a dying parent and child, can endure. Mom's hospice nurse was uncomfortable having this discussion with us, but we realized that she was simply the messenger.

My mother passed away with her cast still on.

To be clear, prior to the pacemaker implant expense, specialty care was never denied while Mom was still enrolled in her MA plan. Mom continued to receive expensive injections to slow her macular degeneration. We were also able to visit the local valve clinic to explore a transcatheter mitral valve replacement to address her leaky mitral valve problem. This option is much better for frail patients because it is much less invasive, although much more expensive. We decided that a new valve would be too risky for Mom, especially because it was addressing a repair (with subsequent biological challenges) rather than an initial valve repair or replacement. It was also unclear if it would substantially improve her quality of life amid the specter of unwanted complications. The Care Coordinator for her MA program was fantastic in seeking out care prescribed by all of Mom's specialists during her entire membership.

Reflections, Policy, and Implications

I was a financial reviewer of health maintenance (HMO) risk arrangements in the 1980s while serving as an external financial consultant for the Health and Human Services' Office of Prepaid Health Care. I helped determine both federal qualification and compliance (the latter when HMOs ran into various financial and operational difficulties). I witnessed many types of contractual arrangements, some of which could put even the individual clinician as well as hospitals in the position of foregoing risk pool payouts. This aggressive form of risk sharing is not allowed under Medicare Advantage regulation.

Under 42 CFR § 422.208, "The MA organization makes no specific payment, directly or indirectly,

to a physician or physician group as an inducement to reduce or limit medically necessary services furnished to any particular enrollee.”³

In retrospect, I queried long and hard: what would have caused Mom’s primary care physician to pronounce that she had less than six months to live? I was familiar with difficult “end of life” discussions, particularly as my former healthcare delivery system employer and clinicians were early champions of palliative care.⁶ I later learned that when terminally ill patients transition from Medicare advantage to hospice, the MA plan can no longer be at financial risk for medical services as the option for a move to traditional Medicare becomes available.² As Mom was on the downward trajectory, the Medicare premiums received by her MA plan for services were clearly exceeded by her expenses for the care she had been receiving and most likely for future care. While this conclusion is clearly my educated speculation, Mom’s primary care physician and “gatekeeper” was accountable for her care and related costs, as well as indirectly responsible for the relationship between the medical group and the insurer of the MA plan. It now appeared to be in their “best interest” to preserve this relationship by jettisoning Mom and avoiding her medical costs as quickly as possible.

From a policy perspective, in the face of rising medical costs, there should be better ways to incentivize providers and insurers of MA plans to care for terminal patients, and especially those who are on hospice. However, one major positive from Mom’s physician’s pronouncement was that I spent as much time as possible taking care of her. I shared that responsibility with her caretaker during the day and with my wife and daughter during night and weekend duty. We had to employ care aides in the evenings and during the night, and we were fortunate to be in the financial position to afford them. While the unit cost of that care is not expensive, the number of units makes the total care expensive.

While remaining in the MA plan is apparently listed now as an option by CMS⁴, I do not recall that option being offered or explained. Rather, the hospice nurse told us that traditional Medicare would continue to cover non-terminal services per CMS. It seemed that the Medicare Advantage plan automatically transferred my mother from their plan to Medicare.

Medicare Advantage plans under the Affordable Care Act appear to have been created to produce greater certainty around federal outlays and budgeting by shifting risk, i.e., uncertainty,

to external entities. Under global risk models, insurance companies have further shifted financial accountability to physician groups.⁵ Recent pushback has occurred as both physicians and hospitals have been declining contracts with insurance companies and their MA plans. Their rationale: increasing requirements to provide care have become burdensome for providers. They are no longer accepting their patients' coverage, with patients bearing the brunt of these financial decisions. Patients are left to find new providers.⁷

Conclusion

The U.S. healthcare system remains complex and daunting, even for someone who has spent a 40-plus-year professional career studying and participating in the system. I have been employed by the federal government, a private insurer/administrator for a state Medicaid program, a consulting firm, a healthcare delivery system, and now, a university. Sadly, these broad experiences still do not prepare someone for the challenges of caring for a dying relative. The accomplishments and life experience both professionally and personally can matter little for the terminally ill and their families – although financial resources can alleviate at least some of worry. Medicare Advantage plans and their contracted providers will continually be incentivized to make decisions with increased weight on financial considerations rather than patient and family needs. One would hope, however, that the government and private payers could incentivize actions on the healthcare delivery side to be more humane during the struggles that families endure when a member is terminally ill.

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