Medicine and Money

Financing of care for fatal chronic disease: opportunities for Medicare reform

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CASE REPORTS OF CONTRASTING CARE PATHWAYS

Ordinary course of care

Mary Smith, 78 years old, had osteoporosis, diabetes mellitus, mild heart failure, cataracts, and breast cancer. Her husband, 84 years old, had cognitive impairment and, since having a stroke, was dependent for transfers, bathing, and dressing. They lived on a small pension in a rented apartment. Their children lived at a distance, and the Smiths had few contacts except for health care. During the turmoil and financial challenges of Mrs Smith's cancer treatments, Mr Smith worsened and entered a nursing home. Mrs Smith wore herself out with worry, and her heart failure worsened. Mr Smith died in a hospital intensive care unit of a urinary tract infection. She

Summary points

- Comprehensive and high-quality care for persons with eventually fatal chronic illness can be an adverse business strategy for providers
- Payment arrangements for hospice, comprehensive eldercare, and veterans offer promise of better policies
- Severity of illness and expectation of declining status should trigger tailored services and payment policies, rather than linking services to limited prognosis
- Wise policy reform requires commitment to testing innovations

developed back pain and constipation but would not go to her physician's office for an evaluation. Eventually she became delirious and was admitted to the hospital as an emergency. She could not keep her apartment and entered a nursing home. A few months later, Mrs Smith also died in the hospital, after being transferred because of pulmonary edema. Through all this, the Smiths had a dozen different physicians, several hospitalizations (including dying in the hospital), and much suffering.

Better course of care

Mrs Smith's physician recognized that the Smiths' situation was rife with risks. As soon as she was diagnosed with cancer, Mrs Smith's physician involved a nurse care coordinator who worked with the Smiths through the rest of their lives, planning ahead and marshalling needed services in a timely way.





Table 1 Estimates of Medicare reimbursements and provider income for the Smiths' ordinary care and better care scenarios*

Service	Production cost, \$	Ordinary care Medicare payment, \$	Provider net income, \$†	Production cost, \$	Better care Medicare payment, \$	Provider ne income, \$t
Home nursing visits	200	210	10	3,000	2,300	(700)
Physician office visits	600	350	(250)	100	120	20
Physician home visits	0	0	0	1,000	450	(550)
Physician hospital visits	2,000	2,300	300	0	0	0
Care coordination	0	0	0	3,000	500	(2,500)
Hospitalizations	20,000	21,000	1,000	0	0	0
ED and ambulance	1,500	2,000	500	0	0	0
Total	24,300	25,860	1,560	7,100	3,370	(3,730)

ED = emergency department.

*We have estimated amounts from the committee's experience and from published tables of Medicare reimbursements. Estimates exclude costs that are not generally covered by Medicare, such as nursing facility, home health aide, and assisted-living facility costs.

†Provider net income is the difference between the payments and the costs of production, which include salary costs for the professionals and their practice costs. Numbers in parentheses represent net losses.

The care coordinator contacted the Smiths' old church and elicited some friendly visitors and volunteer help. The city provided inhome aides and repair services to enable them to stay at home, even when chemotherapy left Mrs Smith fatigued. When Mr Smith had another stroke, a home care program helped for a few weeks until he died at home. Mrs Smith had more trouble with shopping and housework due to heart failure, so she moved to senior apartments that provided meal and maid service. She passed away quietly one night.

INTRODUCTION

Could financing arrangements influence whether the "better course of care" could become commonplace? Some shortcomings in care for patients with eventually fatal chronic conditions arise from inadequate professional education and quality standards,1 but health care professionals and expert panels also claim that inappropriate Medicare coverage and payment policies perpetuate dysfunctional arrangements in the care system.^{2,3} In this article, we show how financing might contribute to the perpetuation of inadequate care and suggest remedies for such situations.

Three fourths of Americans die past 65 years of age.1 Thus, Medicare policy structures the pattern of care received at the end of life. More than three quarters of those dying in Medicare have chronic heart or lung failure, cancer, stroke, or dementia.⁴ Not only are most people very sick just before death, they also will have been very sick for many months earlier. During that time, they often receive care that is unreliable, inadequate, inappropriate, unwanted, and costly.1,5,6 Medical care in the last year of life accounts for 11% of overall health care spending and 27% of Medicare spending.^{7,8}

METHODS

This article arises from discussions of a panel of experts convened by the American College of Physicians and the American Society of Internal Medicine. The literature cited in this article came from 3 sources: a review composed for a meeting convened by the Project on Death in America and the Robert Wood Johnson Foundation in 1999, a citation search for key articles, and literature suggested by those involved in the panel and researchers in the field. A convenience sample of a few large practices provided estimates of costs and Medicare reimbursements, which we checked against published rates for Medicare reimbursements and the experiences of members of the panel. The implications of the findings were not sensitive to variations in costs or reimbursements within the range reported from our various sources.

COSTS AND REIMBURSEMENTS

The table presents estimates of service delivery production costs, Medicare reimbursements under the usual fee-for-service program, and resulting net income for each type of provider for each type of care that the Smiths might have had. Prescription drugs and nursing facility care are not included (not covered by Medicare), and the cost of Mrs Smith's outpatient treatments for cancer is not included (it would be the same in both scenarios). The "costs of production" are the estimated costs to the provider to deliver the services, including salaries and overhead.

The table shows that good care actually could cost the Medicare program much less than ordinary care now does-and that this improved care could mean a financial disadvantage to every provider in Medicare's feefor-service system. Capitated managed care is likewise unattractive for ensuring better care for the Smiths. Medicare's capitation rate is not adjusted for the patient's condition, so people this sick cost their managed care provider much more than the provider receives. Thus, capitated providers in Medicare have reason to enroll and retain "healthy" elderly and to make it disadvantageous for patients like the Smiths to be in their programs.^{2,9} Indeed, a reputation for excellence in care of serious chronic illness would attract patients whose Medicare capitation would not pay for the expected costs of care.

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THE CASE FOR REFORM

The reimbursement system probably did not cause the Smiths' "ordinary" care to be commonplace, but it certainly can deter reform and reinforce current practices. Medicare fee-for-service providers receive their best financial return in fragmented systems with little preventive care or planning. Medicare capitated providers receive their best financial return by avoiding special services or a reputation for excellence in caring for very sick people. These considerations ensure an unreliable and poorly performing care system.

Five innovations in current payment policies illuminate possible directions for reform (see first box). First, Medicare pays for hospice services on an all-inclusive per diem basis, mostly at a standard home care rate. 10 If a patient has a life expectancy of less than 6 months and chooses to forgo "curative" treatments, Medicare will pay about \$100 per day for comprehensive hospice services through to death. The administrative details are complex, but the patient and family get continuity, medications, counseling, bereavement support, in-home services, and symptom management. Although no current and reliable research evaluates hospice performance and value, health professionals and family testimonials in the popular press generally agree that hospice programs serve their core population well. However, hospice often cannot help people in situations similar to the Smiths', whose prognoses were too long or uncertain for almost all of the ends of their lives.11

Second, Medicare managed care could adjust payments to reflect financial risk, a strategy that has been enacted by Congress but not yet implemented. If the capitation for persons with serious chronic disease

Examples of arrangements that provide better care

- Hospice
- Risk adjustment for capitated managed care
- The program of all-inclusive care of the elderly
- Innovations for comprehensive care in the Veterans Health Administration
- Coverage for care management

were adequate to support good care, managed care providers would have reason to implement protocols that came closer to meeting the Smiths' real needs. Doing so would improve quality of life and save money. Unfortunately, developing a reasonable method for risk adjustment has proved difficult, and thus, implementation has been delayed.^{12,13}

Third, the Program of All-Inclusive Care for the Elderly (PACE) receives comprehensive capitation from Medicare and Medicaid (public health insurance for the poor) for elderly persons who are living in the community but who are disabled enough to qualify for publicly supported nursing facility care. These programs offer substantial flexibility in the use of pooled funds to support a sizable group of seriously chronically ill persons. The programs have been difficult to replicate, but they appear to satisfy patients and families. The comprehensive funding and service array, through to the end of life, could be appealing features for end-of-life care more generally.

In addition to innovations in Medicare, end-of-life care in the Veterans Health Administration (VHA) has recently been substantially improved, with reductions in pain, enhancements in advance care planning, and better continuity of care. ¹⁴ The VHA serves a group that is more often affected with serious chronic illness than the general population, and it is a salaried system with an annual budget. Although VHA successes show what an organized system can do, the VHA serves only a small proportion of patients facing the end of life.

Medicare could also add a benefit for "case management" services for selected groups with terminal illnesses.2 This would require Medicare to become more like a private-sector managed care plan than a universal fee-for-service insurance program: identifying groups in need of such benefits, selectively contracting with providers, and managing care toward improvement targets. This approach would have had obvious application to the Smiths' situation. Arrangements allowing preferential contracting have met strong political resistance, but they may be more palatable for persons with serious chronic illness, especially if trials showed improved quality and value.

Key strategies for reform in financing care for the end of life

- Define the target population by severity of illness, not prognosis
- Innovate and evaluate
- · Create accountability
- Provide incentives for continuity, advance planning, symptom management, and family support

CHARACTERISTICS OF BETTER FINANCIAL ARRANGEMENTS

Medicare effectively insulates most patients with eventually fatal chronic illness from financial ruin resulting from physician and hospital costs and helps ensure quick access to these services. Except for limited copayments, the Smiths would not have been liable for any services covered by Medicare in either type of care. Reforms must avoid dismantling these valuable features of Medicare.

If the targeted population is to include those who will eventually die of their serious chronic illness, then the category itself will need clarification and specification. The key components are an illness or condition that will worsen and prove fatal despite treatment, substantial current disability, and the need for ongoing health care. The Rather than being predicated on a statistical claim about prognosis, such a category should turn on indicators of disease severity and disability. The group thus identified would have a predictable relationship of survival to time, but in contrast to Medicare's hospice eligibility, any one patient's prognosis could be uncertain.

Payment arrangements could provide advantages like higher rates, limited capitation for care coordination, or more rapid processing to providers of services that include elements considered desirable to dying patients and families, such as continuity, advance planning, and comprehensiveness.

Existing programs with substantial scope and promise could be expanded. For example, hospice could be allowed to enroll seriously ill patients with persistently uncertain prognoses, and capitation payments to managed care could be adjusted to reflect higher costs for very sick people.

Coverage and payment rates must permit good care to become routine for those

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with serious chronic illness. Those payment mechanisms should also generate attention to quality, accountability, and value.

AN APPROACH TO REFORM

Current debates about the future of Medicare focus on paying less for the current system of care and expanding coverage to prescription medications. For chronic illness at the end of life, these are insufficient. For that last phase of life, the care now provided is not what we want to keep purchasing. Instead, we need a renewed commitment to innovation, evaluation, and learning about the actual effects of alternative arrangements (see box on previous page).

Reform requires evidence that better systems of care are within reach. Some of the needed examples of good care arise from quality improvement efforts at the local level, but success also requires widespread implementation in demonstration projects. ^{16(p163)}

Reform may also require that society identify someone to be held accountable for good care for persons with eventually fatal chronic illnesses. At present, everyone involved can feel that they are merely "cogs in the wheel," with no particular obligation to initiate or monitor change. Perhaps Congress could lay responsibility on a national commission³ or could require annual reports on the state of end-of-life care by the Surgeon General, a

National Institute of Health, or the Secretary of Health and Human Services. ^{1,7} Various strategies could ensure that an enduring agency be held accountable for overall system performance and improvement.

Learning to provide reliable, high-value care in a financially sustainable way will require an array of reforms—in professional education, public expectations, care system engineering, financing, and elsewhere. The Smiths' contrasting potential stories and the associated financial ramifications for providers show that providing better care for those sick enough to die in the United States is not likely to become standard practice without substantial changes in Medicare financing.

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A call for help

Many of us are brought up from an early age with the story of the good Samaritan. In the original story the Samaritan volunteered his services. Doctors, however, are obligated by society to come to the aid of people in need, even when they are off duty. I suspect that many worry about this prospect as much as I do.

A few months ago, I was relaxing in the coffee lounge of a large hotel after an anniversary dinner with my wife. The agreeable postprandial peace was suddenly interrupted by a loud, high-pitched scream coming from the hotel lobby. Shortly afterwards bedlam began. A rather flustered, severe looking, middle-aged woman began rushing round frantically asking for help. "Call the police, call an ambulance." she shouted.

middle-aged woman began rushing round frantically asking for help. "Call the police, call an ambulance," she shouted.

I got up, rather reluctantly, I admit, and went over to investigate. The first thing that surprised me was the number of onlookers that had gathered, perhaps up to 20 people. Most of them seemed to be hotel guests with some anxious looking staff members mxed in. Naturally, none of them seemed to be doing anything useful, just looking a bit awkward and avoiding eye contact with each other.

I made my way through the crowd, trying not to be too conspicuous, until I saw the cause of the commotion, a young woman lying on the floor. An initial glance showed she wasn't moving, and she seemed to be unconscious. I also noticed a large bump on her forehead. Action was needed and fast, I thought. I took control, pushed my way through to her, muttered "Airway, breathing, and circulation" to myself, and knelt down beside her.

Suddenly, before I could perform any heroics, I was grabbed forcibly from behind. I looked round to see who was interrupting my lifesaving work. The middle aged woman who had been asking for help was looking even more flustered and severe than before. "What are you doing, what are you doing?" she shouted at me. I felt the burden of the gaze of the crowd, which had now swollen to about 30 people.

In a need to justify my presence an inspirational line came to me: "Don't worry, dear. I'm a doctor."

There was an unnerving pause, and her face changed, she grinned, leaned toward me, and whispered in my ear, "Don't worry, doctor. It's a murder mystery party."

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