The proportion of deaths occurring in nursing homes has steadily increased over the past few years. Recent data from North Carolina and Maine suggest that the rate may be as high as 30 percent. This trend is spurring interest in an agenda to improve the quality of end-of-life care in these facilities. Innovative initiatives include training modules in palliative care, regional ethics committees to facilitate decision-making, and the development of quality indicators. (See the other publications in this mini-series for a discussion of these initiatives.)

To ensure that the needs of dying residents are met, this agenda must address financial factors as well. Methods of payment, for example, affect the level of care and the mix of services that are available in nursing homes. Unfortunately, the complexity of the reimbursement system and confusion surrounding recent changes associated with the Balanced Budget Act of 1997, it seems, have hindered dialogue in this area.

This publication offers a framework for examining the impact of reimbursement on end-of-life care in nursing homes. Drawing on interviews with providers, researchers and policy makers, it identifies the major payers, discusses the significance of budgetary constraints and financial disincentives, and highlights potential areas for research.
Who Pays for End-of-Life Care in Nursing Homes?

Nursing homes are reimbursed for end-of-life care in different ways, depending on who pays the bills. Some residents are covered by private insurance policies. Others pay for their own care, at times impoverishing themselves in the process. In most cases, however, Medicare or Medicaid is involved.

Medicare

Medicare, a federal program administered by the Health Care Financing Administration (HCFA), provides benefits for the elderly and disabled. The program has two components: Part A and Part B. Part A covers hospitalization and a range of other services, such as skilled nursing care and hospice care for nursing home residents. Part B covers routine doctor visits provided in any setting, including nursing homes. While Part A and Part B are designed as a package, residents can qualify for coverage under one without receiving benefits under the other.

Medicare payments to nursing homes increased dramatically between 1986 and 1996. The Prospective Payment System, enacted in 1997 to reduce the rate of growth, was initially projected to generate savings of $9 billion over five years.

Skilled Nursing Benefit (Medicare Part A)

Patient Example

An elderly woman, who lives alone, suffers a stroke and falls down. She remains on the floor, unable to move, for an extended period of time before she is discovered by a neighbor. After several days in the hospital, the woman is discharged to a nursing home with an uncertain prognosis. In addition to a pressure sore on her hip, she has partial paralysis and speech deficits. Her appetite is poor, and she often chokes when she swallows food. She is confused and unable to communicate, but her living will states that she does not want CPR or a feeding tube. She qualifies for the skilled nursing benefit because she needs wound care for her pressure sore.

Under the Part A skilled nursing benefit, patients who require post-acute care after a hospital stay can be admitted to a nursing home for up to 100 days. The benefit covers room, board, skilled nursing services, minor medical supplies, therapy, drugs, and lab services.

Until recently, nursing homes were reimbursed by Medicare on a fee-for-service basis. While this insulated facilities, to some extent, against increased costs associated with caring for residents who are older and sicker, the impact on the federal budget was significant. Between 1986 and 1996, Medicare payments to nursing homes grew very rapidly, from $450 million to $8 billion (see chart below). To stem this increase, Congress introduced a prospective payment system (PPS) as part of the Balanced Budget Act of 1997.

Under the PPS, Medicare beneficiaries who reside in a nursing home are assigned to one of 44 Resource Utilization Groups (RUGs) based on a clinical assessment. Residents in the most service-intensive classifications—“Rehabilitation,” “Extensive Services,” “Special Care,” and “Clinically Complex”—automatically meet the criteria for a “skilled stay.” Each RUG translates into one per diem payment for all routine, ancillary and capital costs associated with the individual’s care. The payment represents an average—nursing homes will spend more on some residents and less on others. Rates are based on actual costs from 1995, with modest adjustments for inflation. They are being phased in over a three-year period.

The transition to the PPS has been difficult for many nursing homes, especially those with less sophisticated systems for projecting and tracking costs. Because of a lack of objective research data, however, it is hard to determine whether patient care is being compromised (see “The PPS: Facts, Claims, and Counter-Claims” on page 5).
Hospice Benefit
(Medicare Part A)

Patient Example
A nursing home resident is diagnosed with inoperable lung cancer. In consultation with his physician and his family, he elects the Medicare hospice benefit because he wants to receive comprehensive palliative care. Although he will have to pay for his own room and board, he chooses to stay in the nursing home where he has been living for almost a year rather than move in with his niece who lives hundreds of miles away.

Medicare Part A also covers hospice for beneficiaries who are expected to survive less than six months. In contrast to the RUGs-based “skilled” benefit, the hospice benefit is explicitly designed for end-of-life care, including pain management, supportive services, and bereavement counseling.

Although hospice is available in many nursing homes, fewer than one out of every one hundred nursing home residents is enrolled in hospice, according to research conducted at Brown University’s Center for Gerontology and Health Care Research.

Why aren’t more people participating in hospice? A number of impediments have been identified, including uncertainty about the course of illness and cultural attitudes about dying. While the decision ultimately falls to the patient and his or her physician, there may be some financial disincentives for nursing homes to refer residents to hospice:

• Medicare rates are lower for hospice than for skilled nursing care. As a result, nursing homes lose revenue when a “skilled resident” elects hospice.
• The Medicare hospice benefit does not include room and board, so residents have to pay these costs out-of-pocket. The vast majority of hospice patients elect to receive services at home instead.
• HCFA’s rules and regulations concerning hospice are not always interpreted consistently by fiscal intermediaries, says Joan M. Teno, M.D., M.S., associate medical director of Hospice Care of Rhode Island. In this context, nursing homes may be reluctant to make referrals because of uncertainty and perceived risk.

Supplemental Medical Insurance
(Medicare Part B)

Medicare Part B covers routine doctor visits for nursing home residents who qualify. It requires an additional payment, however, so some qualified individuals choose not to participate.

There are three major limitations that directly affect end-of-life care under Part B. First, room and board are not included, creating a discontinuity of care for dying patients who have to leave the nursing home when their Part A coverage ends. Second, there is no prescription drug benefit, so many patients have to pay for their own pain medications. Third, although physicians are reimbursed for consultations, the rate is not adjusted to reflect the additional time needed to address adequately the unique concerns of people who are approaching death. The impact of the first two factors is mitigated, of course, if residents are eligible for additional benefits through Medicare Part A, Medicaid, or private insurance.

Some special services—like assisting patients with advance care planning—are considered part of “routine care,” so nursing homes are not eligible for any additional reimbursement.
Medicaid

Patient Example

A woman with advanced Alzheimer’s Disease is placed in a nursing home when her daughter can no longer care for her. She does not qualify for skilled or hospice care under Medicare, so her bills are paid out-of-pocket. Within four months, her savings and assets are gone (“spent down”) and she becomes eligible for Medicaid.

Medicaid, jointly funded by federal and state taxes and administered by the states, covers low-income and medically needy people. Benefits include skilled nursing care as well as room and board in a nursing home. Medicaid also helps “dual eligible” residents—those who qualify for benefits under both Medicaid and Medicare—cover their Medicare premiums and co-payments.

Since Medicaid eligibility criteria and reimbursement rates are established at the state level, there is significant variation across the nation. In general, however, Medicaid per diem payments to nursing homes are significantly lower than those provided by Medicare or private insurers.

Most states offer a flat daily rate that covers routine care for all Medicaid beneficiaries, rather than adjusting the rate to reflect different levels of acuity. This can create disincentives for nursing homes to admit people who require a high level of care—including those approaching death.

Dying patients face additional risks if ancillary costs are bundled with routine costs. According to a recent study by Abt Associates, providers are less likely to prescribe costly drugs under this arrangement than if they are reimbursed separately for ancillary costs on a fee-for-service basis. The implication is that the quality of end-of-life care and pain and symptom management may be jeopardized—a risk associated with any effort to contain costs.

Most states offer a hospice benefit under Medicaid. Like Medicare’s program, however, it is rarely used. There are at least two financial barriers to Medicaid hospice referrals. First, the nursing home often receives a reduced room and board payment when a resident enrolls in hospice. This adjustment is based on the assumption that the hospice provider will offset some of the nursing home’s costs. While the reduction is small, it represents a disincentive for nursing homes that may already be operating close to the margin. Second, when a resident enrolls in hospice, the full Medicaid payment—including the nursing home’s share—is sent to the hospice provider. Despite the fact that the terms of the agreement between hospice and the facility are negotiable, some nursing homes are not comfortable with this financial arrangement.

Navigating this complex network of public and private payers can be very challenging for nursing homes. During the admissions process, the staff examines all possible sources of financial support available to a prospective resident.

Once residents are admitted, reimbursement can affect continuity of care. Nursing homes have a financial incentive, for example, to reserve certain beds for residents who qualify for skilled nursing care. This means that the end of a “skilled stay” may trigger a transfer—to a different room, a different floor, or even a different building. In addition to being disruptive for residents and their families, these transfers can interfere with good end-of-life care—especially if residents end up dying in an unfamiliar environment among strangers.

Regulations designed to protect dying patients, meanwhile, may be undermined by inadequate funding. A provision of the Patient Self-Determination Act of 1990, for example, requires nursing homes to discuss advance directives with all new residents. Given the nature of the subject, this task can be time-consuming and staff-intensive, yet it is considered a “routine” cost, so nursing homes are not reimbursed separately for it. As a result, staff who are often already overextended and underpaid are forced to take on additional responsibilities, according to many nursing home professionals.

Continues on page 6
The PPS: Facts, Claims, and Counter-Claims

Does the PPS reflect the needs of dying patients?
The PPS has not altered the eligibility criteria for dying residents under Medicare Part A. The definition of skilled care still includes references to activities such as management and evaluation, observation and assessment, and patient education, all of which are relevant to end-of-life care.

It has, however, created some potential disincentives to providing palliative care:

• There is no RUG specifically designed for dying patients. Instead, they are assigned on the basis of a clinical assessment instrument known as the Minimum Data Set (MDS). While the MDS includes questions about the frequency, intensity, and site of pain, other palliative measures—like positioning and turning and psychosocial care—are not incorporated.
• Anecdotal evidence suggests that reimbursement rates do not adequately reflect the high costs of state-of-the-art pain management. Pain medications can be very expensive, especially if high doses are prescribed or if the methods of preparation or administration require special skills.
• RUGs that emphasize rehabilitation are reimbursed at the highest rates, yet rehabilitation services are not usually appropriate for dying people. Of course, higher rates do not necessarily translate into greater profits for nursing homes since facilities generally spend more to provide these services.

Congress has acknowledged that initial reductions in payments associated with the implementation of the PPS were too severe. The FY 2000 spending bill raised per diem rates across the board by 4 percent for two years and boosted rates for certain RUGs—including the “Clinically Complex” category—by an additional 10 percent on a temporary basis. In addition, HCFA has hired Abt Associates, a research firm, to determine whether other rate adjustments are necessary. High costs associated with pharmaceuticals and other ancillary services may be more accurately reflected when adjusted rates go into effect on October 1, 2000.

Is the PPS affecting access to care for the most vulnerable patients?
Prior to 1998, HCFA established reimbursement rates for Medicare Part A, but nursing homes that incurred unusually high costs could request an adjustment by filing a “cost report.” If the costs were reasonable, the adjustment would be granted.

Requests for adjustments are no longer accepted under the PPS, forcing facilities to assume more financial risk when they admit a seriously ill or dying patient. “The stakes are higher now because of the new financial constraints,” says Terry Hill, M.D., medical director at Laguna Honda Hospital in California.

The Office of the Inspector General (OIG) of the U.S. Department of Health and Human Services has been charged with monitoring the impact of the PPS on access. According to a recent study conducted by the OIG, 20 percent of hospital discharge planners say that it has become more difficult, but not impossible, to refer complex patients to nursing homes. A number of providers challenge this finding, however, citing instances in which dying people ended up in facilities that were inadequately staffed or far from home. They say the report fails to reflect the human costs associated with this practice.

PPS Glossary

Prospective Payment System (PPS)
As mandated by the Balanced Budget Act of 1997, nursing homes now receive a per diem payment for the routine (e.g., room, board, nursing services, minor medical supplies), ancillary (e.g., therapies, drugs, lab services), and capital (e.g., land, building, equipment) costs associated with each resident’s care under Medicare Part A. Rates are prospectively determined on the basis of the resident’s clinical characteristics.

Resource Utilization Groups (RUGs)
Nursing home residents are assigned to one of 44 RUGs based on information from the Minimum Data Set, a clinical assessment instrument. A higher RUG classification indicates that a resident requires more intensive nursing or rehabilitation services.

Health Insurance PPS (HIPPS)
HIPPS refers to the schedule of reimbursement rates associated with the 44 RUGs. Nursing homes receive higher rates for residents in higher RUGs.

Fiscal Intermediary
Fiscal intermediaries are public or private agencies that process Medicare Part A claims submitted to HCFA by service providers, including nursing homes. Often, these are Blue Cross plans or other large insurers. They wield a great deal of power in the interpretation of rules regarding financing.

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Dorothy Fauntleroy, former president, chief operating officer, and administrator of SWOPE Ridge Geriatric Center in Missouri, says that advance care planning is most effectively conducted by interdisciplinary teams, but nursing homes can’t afford to absorb all of the additional costs.

Nursing homes rely so heavily on Medicare and Medicaid that opportunities to generate revenue from other sources are limited. At the same time, cutting costs—by reducing staffing levels, wages, or benefits—could jeopardize the quality of care.

In this context, one might expect financial disincentives to providing end-of-life care to carry additional weight, particularly in poorer facilities without endowments or private investment. But other factors—a commitment to caring for the dying and an appreciation of the benefits of palliative measures—may be mitigating this effect.

Does the current reimbursement system adequately provide for people who are dying in nursing homes? There is a consensus among providers, advocates and policy makers that it could do better. Yet innovation has been stalled due to gaps in knowledge. Joanne Lynn, M.D., director of the Center to Improve Care of the Dying, says that policy makers can help close these gaps by promoting research and disseminating accurate information.

Questions include the following:

- How much does it actually cost to provide an appropriate mix of services, such as pain management, positioning and turning, mouth care, and psychosocial support, to residents who are dying?
- Would nursing home residents have better access to end-of-life care if there were a Palliative Care RUG?
- Has the PPS affected the quality or availability of end-of-life care in nursing homes?
- Since the PPS rates are based on a clinical assessment, how could the assessment instrument be revised to better reflect the needs of dying patients?
- Would hospice referral rates increase if room and board were included in the Medicare hospice benefit? How would costs be affected? Would this create a more seamless system of care for terminally ill patients?
- What can we learn about the impact of state variations in Medicaid reimbursement rates and policies on end-of-life care?

To foster research about finance issues related to end-of-life care, The Robert Wood Johnson Foundation is currently soliciting proposals through its “Changes in Health Care Financing and Organization” grant program. For more information, visit the foundation’s Web site at http://www.rwjf.org.