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End-of-life care in the United States: policy issues and model programs of integrated care

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Abstract

Background: End-of-life care financing and delivery in the United States is fragmented and uncoordinated, with little integration of acute and long-term care services.

Objective: To assess policy issues involving end-of-life care, especially involving the hospice benefit, and to analyse model programs of integrated care for people who are dying.

Methods: The study conducted structured interviews with stakeholders and experts in end-of-life care and with administrators of model programs in the United States, which were nominated by the experts.

Results: The two major public insurance programs—Medicare and Medicaid—finance the vast majority of end-of-life care. Both programs offer a hospice benefit, which has several shortcomings, including requiring physicians to make a prognosis of a six month life expectancy and insisting that patients give up curative treatment—two steps which are difficult for doctors and patients to make—and payment levels that may be too low. In addition, quality of care initiatives for nursing homes and hospice sometimes conflict.

Four innovative health systems have overcome these barriers to provide palliative services to beneficiaries in their last year of life. Three of these health systems are managed care plans which receive capitated payments. These providers integrate health, long-term and palliative care using an interdisciplinary team approach to management of services. The fourth provider is a hospice that provides palliative services to beneficiaries of all ages, including those who have not elected hospice care.

Conclusions: End-of-life care is deficient in the United States. Public payers could use their market power to improve care through a number of strategies.

Keywords

end-of-life care, palliative care, nursing homes, home care

Introduction

End-of-life care—the period of time when patients are seriously ill with the condition that will cause their death—in the United States is fragmented and uncoordinated, with little integration of medical and long-term care services. The SUPPORT study, the largest research project examining end-of-life care in the United States, found that, far too often, people die in pain, isolation and perhaps needless expense [1]. A U.S. Institute of Medicine report concluded that ''people have come to both fear a technologically over-treated and protracted death and dread the prospect of abandonment and untreated physical and emotional stress [2].''

Using quantitative measures of adequacy, Last Acts, a foundation-funded initiative to improve end-of-life care, found that policy and availability of services and care in the vast majority of American states were inadequate [3]. Measures included advance directive policies, location of death, hospice use, the availability of specialised end-of-life services in hospitals, use of intensive care units in the last six months of life, prevalence of persistent pain among nursing home residents, state policies on use of prescription drugs to control pain, and availability of palliative care-certified physicians and nurses. For example, in 1999, in all but one state (Hawaii), 35 percent or more of nursing home residents, many of whom were dying, were in persistent pain. Even worse, more than 40 percent of residents who were in pain at their first pain assessment were still in severe pain 60 to 180 days later [4]. Another recent study found that many dying nursing home residents who are in daily pain receive either inadequate pain treatment or none at all [5].

Medicare, the social insurance program for older people and some persons with disabilities, and Medicaid, the federal-state health care program for the low-income population, are the main sources of financing for end-of-life care in the United States. Private insurance, although providing health care for most Americans, covers a relatively healthy, younger population that dies relatively rarely.

Although Medicare and Medicaid play a large role in financing a wide range of services, the program only covers palliative care—a constellation of services including medical, psychological, social, and spiritual support for dying persons—under the hospice benefit. In contrast to Europe where hospice is primarily an institutional service, hospice care in the United States is almost exclusively provided in the home, with very little use of institutional services. The hospice benefit has the goal of integrated care: a single entity—the hospice—receives an all-inclusive payment to provide virtually all care that a dying individual needs and is responsible for doing so in a co-ordinated fashion that emphasises social care and pain management. Although hospice dominates the policy discussions, the role of Medicare and Medicaid in end-of-life care is much larger than the provision of hospice care, but has received little attention from policymakers. This article addresses the public sector's role in financing health and long-term care services at the end of life by focusing on the structure of public benefits and by describing four innovative delivery systems that provide palliative services to dying low-income beneficiaries outside of the traditional hospice benefit.

Research methods

To supplement the limited research and data on end-of-life care for Medicare and Medicaid beneficiaries, we designed a qualitative study of the program's role in caring for dying patients. Based on a review of the literature on Medicare and Medicaid's role in end-of-life care in the United States, we selected 16 national experts to interview regarding these programs' policies on end-of-life care and four innovative service delivery systems that appear to provide humane integrated care. The national experts were selected by a review of the literature and by asking selected experts for nominations of other knowledgeable persons.

The telephone and in-person interviews with experts were conducted using a standard questionnaire and lasted on average about one hour. The open-ended questions addressed policy issues surrounding Medicare and Medicaid's coverage of end-of-life care, including eligibility standards, covered benefits, quality assurance, and payments issues. We also asked experts to nominate health systems that they believed were providing vulnerable populations with a comprehensive array of high-quality palliative care services.

Experts nominated five health care systems. We chose four of them for in-depth study. The four we chose provide innovative, comprehensive palliative care to Medicaid beneficiaries at the end-of-life; these beneficiaries are poor and many have severe disabilities or are frail older persons. The fifth system, which we did not include in our study, largely serves a privately-insured, middle-income population. We excluded this system because the lack of Medicaid long-term care financing for most dying patients limited the services that they could receive.

We contacted each of the four health care systems and interviewed their program directors. The telephone interviews involved use of standard set of open-ended questions that addressed how the systems organised the delivery of services, how they assured quality, and the type of payment they received from Medicaid and Medicare. In addition to the interviews, we conducted internet searches about the study sites. Unfortunately, little independent information was available about the effectiveness of these systems, with the exception of the On Lok program.

Background on public financing of end-of-life care

Medicare and Medicaid are the two main sources of financing of end-of-life care in the United States, each focusing on a different, but overlapping population.

Medicare

Medicare provides primarily acute care services to older people and younger persons with disabilities with significant work histories. It is a non-means-tested social insurance program, funded entirely by the federal government through payroll taxes, voluntary premiums paid by beneficiaries, and general revenues. Not surprisingly, given that the vast majority of people who die are elderly, Medicare is the primary health insurer for more than 80% of the people who die each year in the United States [6]. Services for persons in their last year of life account for 28% of Medicare expenditures, a proportion that has remained constant over the last twenty years [7]. Medicare spending for decedents is approximately six times the amount for surviving beneficiaries [6]. Importantly, however, dying is not synonymous with high costs. Despite the average high cost of decedents, fewer than a quarter of all beneficiaries in the top 5% of expenditures in 1998 were beneficiaries who died [8].

Although Medicare beneficiaries who die use a wide range of services, the hospice benefit is the primary focus of end-of-life care policy. Most Medicare decedents, however, do not use hospice care, although the proportion has been increasing. Approximately 23 percent of Medicare beneficiaries who died in 2000 took advantage of the hospice benefit [6]. In an analysis of data from 1995 to 1998, decedents under age 65 who were eligible for Medicare because of a disability or end-stage renal disease, were less likely to choose hospice as were minority beneficiaries [8]. While persons with cancer diagnoses account for half of all hospice enrollees, non-cancer diagnoses have grown considerably over the last decade. The program spent $3.6 billion on the hospice benefit in fiscal year 2001, about 1.5% of total Medicare spending [9,10].

Medicaid

Medicaid provides health and long-term care coverage to children, parents, people with disabilities, and older people with low incomes and few financial assets and persons with high medical expenses; non-disabled adults without children are rarely covered. Importantly, Medicaid is the major source of public financing for long-term care services. The program is jointly funded by the federal and state governments and administered by the states under federal guidelines. States have wide latitude in determining eligibility standards for Medicaid's 43 million beneficiaries, the benefits participants receive, and payment to providers. States must provide a core set of services that includes physician, hospital, nursing home and home health care and can choose to offer certain other services including outpatient drugs, hospice and long-term care in the home and community. States can place limitations on any of these services, which may be problematic for persons who are dying. For example, Alabama covers only 16 days of hospital inpatient care and Texas limits the number of prescriptions many beneficiaries can fill to three a month [11, 12].

Medicaid's role in end-of-life care varies depending upon the population under consideration. Most children, parents and adults with disabilities without substantial work experience who meet Medicaid's financial eligibility criteria rely almost exclusively on Medicaid for financing their end-of-life care. However, elderly and younger disabled Medicare beneficiaries who are also eligible for Medicaid (the so-called ''dually eligible'') rely on Medicare for coverage of physician, hospital, and most hospice services during the end-of-life. For the dually eligible population, many of whom reside in nursing homes, Medicaid supplements Medicare by funding such services as outpatient prescription drugs and long-term care and by paying Medicare premium and cost sharing requirements.

Medicaid plays a major role in financing care at the end of life. About one fifth of Medicare beneficiaries who died between 1994 through 1998 were also eligible for Medicaid and Medicaid accounted for almost one third of dually eligible beneficiaries' health and long-term care expenditures during the last six months of life [6]. Much of Medicaid's funding for the dually eligible population is for long-term care, especially nursing home care, at the end of life. Approximately 35 percent of older people who die use nursing home care during the last year of life and an unknown additional percentage use home and community-based services, such as personal care [7]. Because of its high cost, more than two-thirds of nursing home residents are dependent on Medicaid to finance their care [13].

Despite the large role of nursing homes in end-of-life care, the Medicaid benefit specifically designed to serve dying beneficiaries is the optional hospice benefit, which very closely tracks Medicare's benefit. In an analysis of data from 1995 to 1998, approximately 13% of dual eligibles who die elect the Medicare hospice benefit, much less than the proportion of Medicare beneficiaries overall [8]. Every state but Connecticut, Nebraska, New Hampshire, Oklahoma, and South Dakota covered hospice under Medicaid in 2001. In federal fiscal year 2001, Medicaid spent $547 million on hospice services, slightly more than two-tenths of one percent of its federal and state spending [14]. Medicaid accounted for about seven percent of total hospice revenues and eight percent of hospice patients in 1995 [15].

Policy issues in hospice care for Medicare and Medicaid beneficiaries

Most of the policy attention to end-of-life care in Medicare and Medicaid revolves around the hospice benefit and its restrictions. The limitations of the hospice benefit fall into several categories—eligibility, benefits, quality assurance, and payment.

Eligibility

For hospice eligibility purposes, the two programs require that a physician certify that the patient has a life expectancy of six months or less if the terminal illness runs its normal course. The rationale for this restriction is that the hospice benefit includes many

services that are not normally available to beneficiaries and, thus, should be limited to persons who can be expected to die in a relatively short period of time. In other words, the primary considerations are those of cost containment.

The prognosis requirement creates psychological and practical barriers. Most importantly, patients, their families, and physicians have difficulty accepting a prediction of death within six months, making them unlikely to use the benefit. This is particularly true for children, whose families and medical providers do not want to give up attempts at cure [16].

Beyond the unwillingness to accept death, the practical problem is that it can be difficult for physicians to make predictions about time of death with a great deal of accuracy, particularly for certain populations. One expert estimated that the date of death is predictable within six months for only 20% of cases and other experts noted that prognosis of children's death is particularly difficult. Children can go in and out of terminal illness phases and the curative process is likely to be very long, making it unclear whether they will ultimately recover from their illnesses [16]. Likewise, the course of illness among persons with AIDS can be quite difficult to predict [17], as it can be for patients with dementia.

Benefits

The Medicare and Medicaid hospice benefit include the same services—skilled nursing care; medical social services; hospice physician services; nutritionist services; short-term inpatient services (for pain control or acute or chronic symptom management and for providing respite for family members); homemaker services; counselling services; home health aide; medical appliances and supplies, including drugs and biologicals; physical and occupational therapy; speech-language pathology services; and bereavement counselling for the patient and family members. In addition, up to five days of respite care is covered. Many of these services, notably homemaker services, counselling services, most outpatient prescription drugs, bereavement counselling and respite care are not normally available to Medicare beneficiaries. For the Medicare program, a $5 co-payment is required for prescription drugs, as is a 5% coinsurance for respite care.

As a condition of receiving these additional hospice services, beneficiaries must agree to forego curative care related to their terminal illness. This restriction reflects Congressional intent that hospice save money or at least not substantially add to Medicare and Medicaid costs. The programs will, however, pay for treatments by other health care providers for conditions not related to the terminal illness. For example, a hospice patient in the benefit because of cancer still could receive treatment for a fractured hip. Sometimes, however, the line between treatment and palliation is not clear cut. For example, chemotherapy and radiation are normally curative treatments, but they can also provide pain relief when used to mitigate the effects of cancer in the end stage of illness. Although hospice patients can return to the normal Medicare and Medicaid programs at any time, this requirement to forego curative care serves to discourage some patients who are unwilling to forego active treatment from enrolling in hospice.

Although Medicaid and Medicare hospice benefits are almost identical, state Medicaid programs have certain other obligations and options. Medicaid programs cannot impose co-payments on hospice patients and the programs must pay Medicare hospice prescription drug and respite co-payments for dually eligible beneficiaries. Medicaid can cover other services that are related to the treatment of terminal illness as long as these services would not be covered under the Medicare hospice program. For example, if a state covers the optional personal care service, its Medicaid program may cover personal care for hospice patients who have no primary caregiver available.

In addition, there are several issues related to prescription practices and drug coverage that could affect Medicare and Medicaid beneficiaries, although they are not specifically financing policies. Opioids fall under each state's controlled substances acts and are subject to stringent restrictions that can make obtaining prescriptions difficult. In addition, since state medical boards often investigate prescriptions that exceed recommended dosage levels, patients needing high levels of pain medications may have difficulty getting prescriptions written. Moreover, pharmacies often have very limited supplies of controlled substances or do not stock them at all, which can make obtaining pain relief medications cumbersome at best.

Quality assurance

Medicare and Medicaid have quality standards governing hospices and, in recent years, issues of pain management and provision of palliative care in nursing homes have drawn the attention of federal policy makers. To participate in Medicare and Medicaid, hospices must meet Medicare's quality standards or

conditions of participation, which require that an interdisciplinary team supervise or deliver a defined set of services based on a written plan of care. And, nursing homes have conditions of participation that require a plan of care for each nursing home resident and focus on rehabilitation and restoring nursing home residents' functioning [18].

Two potential problems result from these rules and procedures. First, a nursing home resident who elects hospice will have two potentially competing plans of care, one from the hospice and the other from the nursing home. The hospice's plan of care likely will emphasise palliation, while the nursing home's plan likely will emphasise rehabilitation and restoration. Unless the nursing home and hospice co-ordinate their plans of care, the resident could be receiving care that is contradictory and inappropriate.

The second problem is that Medicare and Medicaid's quality assurance system for nursing homes does not focus on palliation and appropriate care for dying residents [18]. Thus, the current system may not be doing all it could to promote appropriate care for dying residents or recognise the terminal phases of illness among nursing home residents. As was noted above, a high percentage of nursing home residents, many of whom are dying, have persistent pain.

The Centers for Medicare and Medicaid Services, the federal agency that administers the two programs, has some efforts underway that could lead to improvements in end-of-life care, including a dialogue with the hospice industry about outcomes measures, and funding research on improving measurement of pain in the nursing facility minimum data set, which is the resident assessment instrument that facilities must use for Medicare and Medicaid patients. In addition, they have made grants to enable Florida, Kentucky, New York, Utah, and Virginia to develop Programs of All-inclusive Care for Children (PACC), which will co-ordinate and integrate all health, social, and supportive services for children with life threatening conditions and their families. It is based on the On-Lok model, which is described below.

Payment

Medicare and most Medicaid programs pay hospices a comprehensive, flat amount on a per diem basis based on the type of care provided—routine, continuous home care, inpatient respite care, and general inpatient care. Care for virtually all (95%) of Medicare hospice patients are at the routine home care level, which was $110 per day in 2002 [15]. These payments are intended to cover the cost of hospice patients on average, with some patients costing less and some more. Unlike almost all other Medicaid services where states have complete flexibility in how they set payment rates, states must pay hospices at least federally-set Medicare rates, which states can increase if they choose to do so.

There are at least three payment issues. First, according to most non-governmental experts, the current fixed hospice rate for routine home care is too low to enable hospices to provide the most advanced types of pain relief, as they can involve expensive chemotherapy and radiation treatments. One study sponsored by the National Hospice and Palliative Care Organisation estimated an average 10–20% shortfall between the costs of delivering care and Medicare's reimbursement [19]. The primary reasons are that the rate does not adequately take into account the costs of prescription drugs and outpatient therapies, including radiation therapy, chemotherapy, and diagnostic testing. Indeed, since the information on which payment rates are based on data from the early 1980s (updated for inflation), it is surprising that the payment rates are not more out of line with costs. As a result, beneficiaries who require very expensive medications may face barriers in accessing hospice services [8, 20, 21].

Second, since payment is on a fixed, prospective basis, the payment methodology encourages hospice agencies to avoid costly patients and to limit expensive services. Unlike Medicare reimbursement systems for hospitals, nursing homes, and home health, hospice has only a very crude case mix adjustment. This lack of case mix adjustment is another reason that payment to hospice provides is considered low. Hospices tend to serve patients in the last few weeks before death when care can be particularly expensive, but that is not accounted for in the payment rate. Despite the fact that eligibility begins six months prior to death, the average length of service in hospice was only 48 days in 2000; the median length of service was 25 days [15]. In 2000, 30% of Medicare hospice beneficiaries died within one week of admission [6].

Third, the way in which Medicaid pays nursing homes for hospice patients causes confusion. State Medicaid programs must pay at least 95 percent of the nursing home rate for room and board directly to the hospice, which in turn pays the nursing home. Reportedly, nursing homes rarely accept less than 100 percent of the Medicaid room and board payment, causing hospices to suffer a financial loss. In addition, the nursing home's payment can be disrupted or payment to the hospice can be delayed when changes in payment are made.

Case studies

The four innovative providers of end-of-life care serve very different types of Medicaid and usually Medicare beneficiaries, yet have several key program elements in common. The first is the capitated payment for services that three of the systems share. This form of payment enables the systems to provide the services participants need rather than only providing a restrictive set of services that may not meet all participants' needs. The second feature is that the plans rely on team management to ensure continuity and quality of care; the central element in all four systems is a skilled nurse practitioner who facilitates communication between participant and doctor and manages day to day provision of services. The third feature is that the systems provide comprehensive palliative services designed to meet the broad range of dying participants' needs. Finally, the plans share a systematic approach to quality assurance that relies on measuring teams' performance against certain quality measures.

Description of selected sites

The four case study sites were the Community Medical Alliance, On Lok, EverCare and the Hospice of the Florida Suncoast. The main features of the four programs are summarised on Chart 1. Each of the sites is primarily financed by a combination of Medicare and Medicaid.

The Community Medical Alliance (CMA) is a Boston, Massachusetts-based health care system that contracts with the Massachusetts Medicaid program to provide comprehensive benefits to beneficiaries with advanced AIDS and individuals with severe disabilities, such as muscular dystrophy, in return for capitated payment [22–24]. In 2000, CMA provided services through primary care practices in Boston to 500 Medicaid enrollees of whom 125 were dually eligible for Medicare and Medicaid; about 240 patients had AIDS, 260 had severe disabilities, and 30 were children.

On Lok is a non-profit managed care plan that provides health and long-term care to frail older persons who reside in the community but who are disabled enough to qualify for nursing home coverage [25–28]. In 2000, the plan served 860 enrollees, of whom approximately 90% were Medicaid eligible, at five sites in San Francisco, California. It is the model for the Program of All-inclusive Care of the Elderly (and the Program of All-inclusive Care for Children).

EverCare, a subsidiary of United HealthCare Corporation, is a Medicare managed care plan that provides preventive and primary care to residents of nursing homes and assisted living facilities through nurse practitioner and physician teams [29–31]. EverCare serves 20,000 enrollees who are eligible for Medicare in nine states. Seventy percent of enrollees in the Minnesota site are dually eligible for Medicare and Medicaid.

The 20-year-old Hospice of the Florida Suncoast is a non-profit provider founded by volunteers that serves more than 1,200 patients a day in Pinellas County, Florida [32]. The hospice serves three categories of Medicaid beneficiaries—dying children and adults, AIDS patients, and nursing home residents who are dually eligible for Medicare and Medicaid. About three-quarters of the hospice's AIDS patients and half of its nursing home residents are Medicaid beneficiaries and about eight percent of the hospice's revenue comes from Medicaid.

Capitated payment

All four programs receive payment from Medicare and Medicaid. CMA and On Lok receive capitated payments from both programs, where they are at financial risk for any cost overruns. In exchange for accepting this financial risk, the programs receive the flexibility to go beyond the list of covered Medicare and Medicaid services and provide the care that their enrollees need, including a range of palliative services that hospice does not provide. Evercare receives capitated payment from Medicare for nursing home residents' primary care needs and likewise can provide a broad range of services. Finally, Florida Hospice of the SunCoast receives fee-for-service payments but uses them creatively to provide services under more liberal conditions than other hospices might do. In addition, this hospice has a strong fundraising component that provides it with funds to fill in the gaps in the fee-for-service model that Medicare and Medicaid use to pay hospices.

The payment methods, however, for each of the capitated sites varies. The Community Medical Alliance negotiates capitated payment from the Massachusetts Medicaid program based on costs incurred during the previous fiscal year. In fiscal year 2001, the Community Medical Alliance received $2,564 per member per month for enrollees with AIDS and those with severe disabilities. The rate for technology dependent children was $8,000 per member per month and $3,200 for high risk children and adolescents with major behavioural health problems.

On Lok receives capitated payments from Medicare and Medicaid to cover the costs of all health and long-

Chart 1 Selected features of the case study sites

	Community medical alliance	On lok	EverCare	Florida hospice of the suncoast
Plan sponsorship	Subsidiary of Neighborhood Health Plan – a non-profit managed care plan.	Non-profit managed care plan.	A for-profit Medicare managed care plan, which is a subsidiary of United HealthCare Corporation.	Non-profit hospice.
Population served	All enrollees are Medicaid beneficiaries—persons with advanced AIDS or severe disabilities; and technology-dependent children, high-risk children and adolescents with major behavioral health problems.	Persons age 55 and older who need nursing facility care. About 90 percent of enrollees are dually eligible for Medicare and Medicaid.	Medicare beneficiaries who are eligible for parts A and B and who live in nursing homes. 70 percent are dually eligible for Medicare and Medicaid.	The hospice serves three categories of Medicaid beneficiaries–dying children and adults, patients with AIDS, and nursing-home residents who are dually eligible.
Enrollment	Voluntary.	Voluntary.	Voluntary.	Voluntary.
Composition of team managing care	Physicians and nurse practitioners.	Physicians, nurse practitioners, social workers, therapists, dietitians, and transportation and home-care workers.	Physicians and nurse practitioners.	Physicians and nurse practitioners.
Capitated payments	Annual negotiation of rates with the Massachusetts Medicaid program based on costs incurred during the previous fiscal year.	Medicare's payment is 2.39 times the adjusted average per capita cost. Medicaid's payment is 90% of what the state pays for a nursing home resident in the San Francisco Bay area.	Medicare's payment is the adjusted average per capita cost minus five percent. Medicaid's payment is based on adjusted average per capita cost.	Hospice receives Florida Medicaid rates for physician, nurse practitioner, home-care aide, and hospice services provided.
Quality-assurance methods	Comparison of utilization data to benchmarks, such as admissions to hospital, and frequency of contacts with enrollees, incidence of decubitus ulcers, and immune-system functioning in the AIDS population. Patients also have grievance procedures they can use.	Annual analysis of deaths and comfort care plans. The interdisciplinary teams' performances are compared and education is provided as necessary.	A clinical quality committee meets monthly to discuss quality issues and progress with the plan's quality initiatives. The plan also tracks sentinel events, such as unexpected deaths.	Annual audits of service delivery, tracking of patient and family complaints, and consumer satisfaction surveys. The quality-assurance programs are tailored to the local results on these measures.

term care services. The capitation rate from Medicare is 2.39 times the adjusted average per capita cost for Medicare beneficiaries in On Lok's service area; in 2000, the Medicare payment was $1,350 per month per enrollee. The capitation rate that On Lok negotiated with the state California Medicaid program was $2,650 per month, which is 90 percent of what the state pays, on average, for a nursing home resident in the San Francisco Bay area.

EverCare receives capitated payments from Medicare and is at risk for all Medicare services, except for hospice. From Medicare, EverCare receives a payment equal to the adjusted average per capita cost

minus five percent, which is the routine payment to health maintenance organisations. For dually eligible residents, Minnesota's EverCare site is at risk for all Medicaid benefits that Medicare does not cover with the exception of nursing home care. Minnesota's Medicaid capitated payment rate for EverCare is age and sex adjusted.

Team management

A key component of the delivery systems is their reliance on teams of physicians and nurse practitioners and sometimes other staff to manage services for people at end-of-life. Physicians and nurse practitioners in the Community Medical Alliance have virtually complete authority to allocate resources within the network to meet enrollee needs without risking financial penalties or having to obtain prior authorisation. Physicians and nurses at the Florida Hospice of the SunCoast are responsible for medical management of palliative care for Medicaid patients.

At On Lok, the interdisciplinary team is much bigger—including physicians, nurses, social workers, therapists, dieticians and transportation and home care worker. The team assesses each enrollees needs upon enrollment and at least every three months thereafter. Within six months of enrolling in On Lok, the physician or nurse practitioner on the interdisciplinary team initiates a discussion of the participant's desires regarding end-of-life care. The discussion explicitly addresses the enrollees' preferences about resuscitation, feeding tubes, and aggressive medical procedures; more than 90 percent of enrollees have advanced directives.

In EverCare, the nurse practitioner plays a key role in providing services and is the focal point of communication for facility staff, residents, and family members. One early study found that nurse practitioners improved family satisfaction with several aspects of medical care compared to a control group; however, they did not improve satisfaction by patients [33]. The nurse practitioners visit residents in the facilities at least monthly, with some residents receiving more frequent contact when their conditions warrant it. Typically, nurse practitioner visits occur two to three times a week when patients are actively dying. Physicians visit residents jointly with the nurse practitioner every 120 days and more frequently if the condition of the patient changes.

Palliative services

All of the health care providers make a full range of palliative services available to their dying patients, even if they do not elect hospice benefits. Thus, they provide palliative care earlier in the dying process than is typically the case in most hospices. Enrollees in the Community Medical Alliance and On Lok receive palliative care that is fully integrated into ongoing services, including personal care, pain management, social work and counselling, private duty nursing, psychiatric nursing, and prescription drugs. Although spiritual counselling is not routine in the Community Medical Alliance, the health plan will arrange for it if the enrollee requests.

EverCare provides palliative services that are integrated into the primary care delivery system and the nurse practitioners are required to have skills in pain management, hydration, comfort care and other end-of-life services. EverCare refers residents to hospice when the member would benefit from such services as bereavement counselling. Under hospice, EverCare continues to provide all primary care services to enrollees.

The Florida Hospice of the SunCoast, makes a full range of palliative services available to its patients. It is able to obtain, with aggressive documentation, Medicaid coverage for physician and nursing services related to medical management of patients' conditions, as well as for most pain relief drugs. However, in order to cover supplies and services that Florida Medicaid does not, an organisational affiliate of the hospice—AIDS Services of Pinellas County—conducts community fundraisers.

Quality assurance

The four health care providers assure quality through two mechanisms. First, providers compare the interdisciplinary teams' performances against one another and to benchmarks for quality and by providing extensive training The providers measure such occurrences as patient deaths, decubitus ulcers, high levels of pain, and use this information to provide feedback to the teams who are managing patient care. This constant feedback loop helps the teams to manage the changing needs of their patients over time and to try to ameliorate any outstanding quality problems. Each provider considers different measures related to their particular participants. The Community Medical Alliance compares utilisation data to benchmarks, such as admissions to hospital, incidence of decubitus ulcers, and immune system functioning in those with AIDS. On Lok conducts an annual analysis of deaths that focuses on patient age and location of death, cause of death, determination of whether a comfort care plan was in place, duration of comfort care, and use of services in the last month of life. The perform-

ances of the interdisciplinary teams are compared, and any team with problems receives education about how to improve service delivery.

EverCare has a clinical quality committee that meets monthly to discuss quality issues and progress with the plan's initiatives to improve quality for enrollees, such as trying to increase vaccination rates among enrollees, promoting use of advance directives, and tracking sentinel events such as unexpected deaths associated with changes in medication. Each site reports on its progress in addressing these initiatives to EverCare's local and corporate quality councils. EverCare interacts with nursing home staff by developing teaching programs for staff around the quality indicators and how to prevent adverse events. The plan also works with nursing home staff to co-ordinate efforts to deal with quality problems such as dehydration.

The Hospice of the Florida Suncoast operates a quality management program, which audits service delivery, tracks patient and family complaints, and conducts consumer satisfaction surveys. Each of the hospice's four regional offices in Pinellas County has a quality assurance program tailored to the local results on these measures.

Second, the four systems depend heavily on hiring staff that is knowledgeable in end-of-life care and enhances that knowledge through staff training. The Community Medical Alliance recruits nurse practitioners who have experience serving the health plan's populations—e.g., AIDS patients and persons with severe disabilities. Nurse practitioners also train aides in such skills as proper transfer techniques. EverCare depends heavily on the recruitment of nurse practitioners, making sure that they are comfortable with nursing homes and serving frail, older residents. These nurse practitioners receive extensive training about the plan's approach to delivering primary care in nursing homes and do not have caseloads for six to nine months after being hired.

Conclusion

Federal and state policymakers in the United States are only beginning to attend to the roles that Medicare and Medicaid play as the dominant sources of financing of medical and long-term care for people during their last year of life, roles that reaches far beyond the hospice benefit. However, other than a few small efforts, Medicare and Medicaid are not focusing in a major way on using their market power to encourage or force changes in the way beneficiaries die.

A five-part strategy could help improve quality of care for dying public beneficiaries in the United States. This approach largely could be replicated in other countries. First, a re-examination of policy is difficult without better data about Medicare and Medicaid beneficiaries and their experiences while dying. The data needed include information on causes of beneficiaries' death, location of death, and utilisation and cost of services during the last year of life, and how these vary by payer. These data would help policymakers focus on where and when deaths occur and whether beneficiaries receive sufficient access to hospice and palliative services.

Second, public payers could consciously encourage or require the health systems with which they contract to pay more attention to end-of-life care. A few health systems, especially some managed care plans, are using public funds in innovative ways to care for dying beneficiaries. The Community Medical Alliance, On Lok, and EverCare are examples of innovative approaches to financing and delivering Medicaid end-of-life care that rely on managed care. Obviously, use of managed care plans raises issues of freedom-of-choice of providers and capitation provides incentives for underservice, but this approach also gives providers the ability to use their funds in flexible and creative ways.

Third, government officials could explore ways to fund palliative care and make a range of pain relief measures available through the fee-for-service system. Despite the efforts of the providers profiled in the case studies, provision of palliative services, such as pain management and psycho-social services, to dying patients outside of the hospice benefit appears to be quite limited. In a striking exception, the Florida Hospice of the Suncoast has used the current Medicaid coverage of physician, and nurse practitioner services as well as drug benefits to provide some palliative services to Medicaid beneficiaries outside of the hospice benefit. The goal should be to encourage use of palliative care services earlier in the dying process.

Fourth, beyond reimbursement for palliative care, efforts to better monitor pain management and end-of-life care in nursing homes and home care represents an attractive opportunity for improvement. Public payers could use their overwhelming dominance in financing long-term care services to promote better care for dying beneficiaries by requiring participating providers to do such things as measure and control pain.

Fifth, the current structure of the Medicare and Medicaid hospice benefit should be re-examined. The six-month prognosis requirement, inadequate payment

rates, and the need for quality assurance systems to address palliation and pain management in new ways were all identified as problem areas in this study. Currently, however, no consensus exists about how best to address these issues.

The challenge for the future will be to harness the purchasing power of public programs to improve the services that dying beneficiaries receive. Up to now, they have been the sleeping giants of end-of-life care financing.

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Vitae

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