



Changes in
HEALTH CARE
FINANCING &
ORGANIZATION

Financing End-of-Life Care

Challenges for An Aging Population

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Foreword

More than 2 million people die each year in the United States. Yet, surprisingly, end-of-life health care delivery and financing mechanisms are largely patchwork and little understood by most Americans. The Robert Wood Johnson Foundation's Changes in Health Care Financing and Organization (HCFO) Initiative and Last Acts® Campaign co-sponsored a conference that brought together private and public policymakers, researchers, and providers to bring the complex issues associated with end-of-life care to the forefront of the health care agenda.¹ The meeting yielded a series of thoughtful presentations and stimulating discussions that helped identify the role that public policy plays in organizing, delivering, and financing end-of-life care.

This report explores key themes from the conference and highlights the need for further research. It outlines the current public and private financing systems for end-of-life care and suggests ways that these systems could be updated and improved. For example, it discusses how to build on the success of the 20-year-old Medicare hospice benefit. The report also suggests that the financial incentives for hospitals and physicians be shifted away from reimbursing providers for aggressive, inpatient medicine toward rewarding them for providing palliative care and consultative services outside of the acute-care setting.

Finally, the report describes innovative end-of-life care models, including the Program for All-Inclusive Care of the Elderly (PACE) and BlueCross & BlueShield programs.

Although the HCFO/Last Acts conference was critical in raising the consciousness of stakeholders about the importance of end-of-life care, it represents only one step forward. Conference participants identified many research topics that warrant continued investigation and pointed out that much more needs to be done in the way of research agenda development. Clearly, getting the attention of policymakers who already are inundated with countless health care agenda items will be a challenge.

The Robert Wood Johnson Foundation's Last Acts Campaign has made enormous progress in its efforts to raise awareness at the national, state, and local levels about the need to improve care of the dying. In collaboration with the HCFO program, Last Acts has developed new goals for improving the financing of end-of-life care. Our hope is that this conference report will be translated into new research, with a goal of making positive improvements in cost, access, and quality.

The definitions of and relationship between end-of-life care and palliative care vary among experts, patients, and providers.² In fact, palliative care has broad applications from diagnosis with a serious illness through the end of life. We do not make absolute distinctions between end-of-life care and palliative care in this report. However, we do recommend that policymakers reach consensus on the definitions of these terms before considering changes to current payment systems.



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Introduction

A shift in this country's age demographics has increased the importance of financing end-of-life care. As the number of individuals in need of end-of-life care grows with each passing year, the challenge of providing that care will become more difficult. The health care system, especially those sectors devoted to end-of-life care, will face increasing economic and labor-force stresses in coming decades as a result of elderly Americans living longer than they have in the past. The Medicare and Medicaid programs will bear the brunt of this strain. Policy intervention must occur to alleviate this stress and ensure that resources are appropriately targeted to those in need.

"We are one of those societies that regard death as an option," says Gail Wilensky, John M. Olin Senior Fellow at Project HOPE. American medicine is focused on aggressive, continual treatment, even when such care may be futile. While aggressive treatment should be made available to those who may benefit from it, health care

consumers need to understand that there comes a time when palliative measures may be more appropriate. Both baby boomers and their health care providers recognize the need to work toward an integrated health care system that moves seamlessly from chronic care through long-term care to end-of-life care. "Long-term care necessarily comes into end-of-life care; there is no natural boundary," says Joanne Lynn, director of The Washington Home Center for Palliative Care Studies.

Why focus on end-of-life care when there are so many other health care issues to tackle? "Because it is important to honor the wishes of the dying," says Steven Schroeder, former Robert Wood Johnson Foundation President and CEO. Family members and friends need to understand that death can be peaceful and that delivery of end-of-life care may, in fact, be a less costly alternative to futile, aggressive treatment.

Current End-of-Life Financing Systems

Medicare

Medicare is the largest funding source for end-of-life care, serving more than 80 percent of people who die in the United States each year.³ Approximately one-quarter of Medicare's annual budget is spent on its beneficiaries' last year of life. That percentage has remained virtually unchanged since Congress approved the Medicare hospice benefit 20 years ago. While not without its flaws, the hospice benefit is a success story. It has provided comforting palliative care for countless Medicare beneficiaries and their families.

Developed by Dame Cicely Saunders 30 years ago, the hospice model attempts to ameliorate "total suffering" experienced by individuals near death.⁴ It takes a "whole person" approach to care and involves an interdisciplinary team in providing palliative care and counseling for the patient and family near the time of death.

Several models of hospice care are available in a variety of settings, such as in a patient's home, nursing home, or hospital-based unit. Eligibility rules and restrictions, perceptions and psychological barriers, and payment issues may limit access to hospice care. Most Americans agree that consultation with a physician about palliative care would be beneficial much earlier in the dying process than is typically the case.⁵ In addition, anecdotal evidence suggests that hospice offers enormous comfort to patients and their families.

The Medicare hospice benefit offers 24-hour psychological and social services, pain management, respite care, and spiritual and bereavement counseling. It also covers outpatient prescription drugs, medical supplies, and equipment. In exchange, Medicare beneficiaries forgo curative treatment and must be

certified by a physician as having a life expectancy of six months or less.

While the Medicare hospice benefit is generally considered to be a plus in America's health care system, less than 25 percent of Medicare beneficiaries are estimated to use hospice care, based on data drawn from a sample of Medicare decedents.⁶ Improvements are needed to make the system more accessible, less rigid, more accepted by the dying and their families, and less financially draining for hospice care providers. The following are some of the pressing challenges that require attention.

Insufficient Per Diem Rates

The fixed Medicare per diem rate that is paid to hospice providers often is insufficient to cover daily services. This is particularly true in the case of patients who have short hospice stays with extraordinary expenses.⁷ The first and last few days in hospice are the most costly. Thus, during shorter stays, there are fewer less costly days to offset the more costly ones,⁸ resulting in a financial burden for the hospice facility.

The current per diem rate also fails to take into account recent and costly advances in pain and symptom management.⁹ Moreover, many dying patients do not take advantage of less expensive palliative care options early in the course of their illness. In a May 2002 report to Congress, the Medicare Payment Advisory Commission (MedPAC) noted that current per diem rates, although updated for inflation, are based on data from the early 1980s and "probably are not consistent with the costs that efficient hospices incur in furnishing care."¹⁰

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The Commission recommended a reevaluation of current rates, noting that if hospices that have disproportionate frequencies of short stays are shown to be under-compensated, higher rates could be paid on the first and last days of a hospice stay.¹¹ Alternatively, Medicare could implement more prospective payment tools to cover short episodes of expensive end-of-life care.

Unknown Cost Differential Between Hospice and Non-Hospice Beneficiaries

The relative cost of caring for patients at the end of life through hospice versus traditional care has not been calculated definitively. As Gail Wilensky notes, Medicare originally was designed largely to address acute episodes of care. However, as the baby boomers age, the program must be reconfigured to cover chronic care, including care at the end of life.¹² Making the right cost calculations is complicated.

Although there is evidence suggesting that hospice care may be less expensive than futile medical interventions for those at the end of life, there is no consensus among experts that electing the hospice benefit results in significant savings to the Medicare program or any other funding source. Joanne Lynn and Marilyn Moon, senior fellow at the Urban Institute, suggest that good end-of-life care could cost more;¹³ additional data analyses are needed to answer that question.

Similarly, it is unclear whether non-hospice, palliative care offers savings over traditional, curative treatments. Reliable data are not readily available for calculating such costs, which need to account for sudden death and the cost of treating cancer versus non-cancer patients. Moreover, hospice and palliative care may be correlated with other factors,

such as personal acceptance of mortality, that serve to drive down end-of-life costs.¹⁴ While there are an enormous number of Medicare dollars spent on end-of-life care, surprisingly little research has been conducted in this area.

Six-Month Eligibility Rule Outdated

The requirement that beneficiaries be within six months of their death before becoming eligible for hospice raises a number of concerns. For one, six months is an arbitrary length of time. Many patients are quite sick with chronic, degenerative diseases—their final fatal illness—a number of years before death.¹⁵ Moreover, non-cancer illnesses do not fit easily into a six-month time frame. Physicians may err on the side of being too conservative or too optimistic about their patients' lifespans.

Accordingly, policymakers need to think about ways to modify health care payment mechanisms to take into account the cost of living with a fatal illness.

In addition, while hospice eligibility hinges on a physician's certification that an individual's prognosis is for a life expectancy of six months or less, there is confusion among providers about the interpretation of this language and about the fact that unlimited recertification is permitted. More clarification by policymakers would ease this confusion and perhaps result in more access to hospice care.

Coverage for Palliative Care Outside of Hospice Insufficient

Many patients with predictable and unpredictable end-of-life courses may not participate in the hospice system, but they would nevertheless benefit from palliative care. Currently, the Medicare system does

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not cover a wide array of important palliative care services outside of the hospice benefit.¹⁶ Policymakers may want to consider designing a more structured and explicit reimbursement mechanism for providers who offer non-hospice palliative care,¹⁷ as well as providing prescription drug coverage to Medicare beneficiaries who do not elect hospice.

While adding end-of-life services to the Medicare benefit package may not yield cost savings, a compelling argument can be made that monies spent to provide palliative care support a greater good. In other words, value is achieved by providing quality care at the end of life, regardless of the bottom line. As Moon notes, “when people take more control over their own health care and become better educated about end-of-life options, we may or may not spend less money, but we will likely spend it a lot smarter.”¹⁸

As the baby boomers move toward the end of life, the Medicare program must adjust to address the changing health care needs of a population that will face more chronic diseases with age.

Medicaid

Like Medicare, Medicaid is a significant source of financing for end-of-life care. Approximately 20 percent of Medicare decedents are also Medicaid beneficiaries.¹⁹ Critical among the end-of-life services covered by Medicaid is long-term care, including nursing home and home care. The Medicaid hospice benefit was fashioned after its Medicare counterpart and is covered by most states. However, Medicaid expenditures for hospice care vary dramatically among states.²⁰

The Medicaid program must pay at least federally set rates to cover hospice care for its beneficiaries. However, as with Medicare, hospices argue that

Medicaid reimbursement is not sufficient to cover end-of-life care, particularly for individuals entering the hospice program shortly before death, when expenditures for care are greater.

Medicaid is a significant funding source for nursing home care. Providing nursing home care for those at the end of life, however, poses a unique challenge for the Medicaid program. For beneficiaries who elect the Medicaid hospice benefit, Medicaid pays the hospice. The hospice, in turn, pays the nursing home—but only at 95 percent of the negotiated Medicaid nursing home rates. When a nursing home demands 100 percent of the Medicaid payment rate (which is most of the time), the hospice experiences a 5 percent financial loss.²¹

The fixes needed for the Medicaid hospice benefit are similar to those that should be made to the Medicare hospice benefit. Both programs are plagued with complexities that prevent beneficiaries from fully benefiting from available payment options. Like Medicare, the Medicaid program lacks an innovative, comprehensive plan for providing cost-efficient, high-quality end-of-life care to its beneficiaries. Decision-makers need to reexamine the practicality of eligibility requirements and reimbursement limits, as well as the quality assurance mechanisms of the Medicaid hospice benefit. In addition, it is important for Medicaid decision-makers to identify ways to fund palliative care, beyond the hospice benefit, and at an early stage in the end-of-life process.

Finally, Medicaid directors could use their market power to challenge health plans and providers who serve their

beneficiaries to develop better systems for ensuring high-quality care to those at the end of their life.

Private Sector

Private sector payers offer a wide range of end-of-life benefits and funding mechanisms.²² Even within one commercial insurance company, benefits may vary from state to state.²³

While the private insurance market may not be the dominant source of financing for end-of-life care, private purchasers are powerful agenda-setters that often serve as a guide for public payers. As noted by Samuel Warburton, Aetna corporate medical director, large national purchasers often set the standard for what is included in benefit packages. These purchasers are also an untapped catalyst for making changes in provider contracts and health plans.

Large purchasers have the leverage to challenge health plans to evaluate the quality of their end-of-life benefits and to provide adequate compensation for care. Purchasers have the power to encourage health plans to develop a variety of metrics to evaluate end-of-life care and gauge improvement. By assessing these metrics (i.e., what percentage of beneficiaries elect hospice), health plans will be better able to pinpoint where reforms are needed. Similarly, employees could push employers to include end-of-life services in benefits packages offered to employees and retirees.

Informal Caregivers

The toll that providing end-of-life care takes on informal caregivers, such as spouses and other family members, is often not taken into account when researchers calculate the overall costs associated with end-of-life care. In fact, a significant amount of health care for the dying is paid out of people's pockets. Some informal caregivers leave their jobs to provide care to terminally ill family members, which can be financially devastating.

One way to provide some financial assistance to informal caregivers is through tax incentives. In addition, family caregivers with no employer-sponsored insurance could benefit from financial support to buy into Medicare or private health insurance plans at a reduced rate. Publicly or privately sponsored training programs and respite support for informal caregivers might also prove beneficial.

Pooling Resources

The current payment system is siloed and, as such, does not promote a continuum of care at the end of life. Integrating the major end-of-life care funding sources may offer at least one solution to the challenge of providing comprehensive, cost-efficient, high-quality care. The challenge for policymakers is to develop an innovative financing model that captures the Medicare and Medicaid reimbursements for dual-eligibles and to supplement that financing model with private funding. Such financing could come from commercial payers or individual out-of-pocket reimbursements to create a single pool of dollars for a broad-based end-of-life care program.

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Changing the Financial Incentives of Hospitals and Physicians

The current model guiding the delivery of health care in America—especially end-of-life care—is rooted in the belief that aggressive treatment is the most appropriate care strategy. Although aggressive medicine is indeed warranted for many patients, individuals at the end of life often prefer palliative care, pain management, and the coordination of their goals with those of their families. Unfortunately, the current financial incentives governing how hospitals and physicians provide care are not conducive to palliative approaches.

Joshua Wiener, principal research associate at the Urban Institute, and Jane Tilly, senior research associate at Urban, have analyzed sites providing care for a large number of Medicaid beneficiaries. They found that in programs that relied on capitated payment mechanisms, providers had flexibility to offer palliative care services without the restrictions imposed by fee-for-service systems.²⁴

Hospitals, which make money on inpatient stays, have no financial incentive to promote palliative care and end-of-life care at home. The current siloed payment systems are designed primarily to support acute, episodic care, rather than chronic and advanced illness. Because there are few provider incentives that promote at-home care, terminally ill patients typically remain in the hospital, where they continue to receive expensive, high-technology interventions that often prove futile.

In addition, negative financial incentives discourage physicians from recommending hospice care. Under the current payment system, providers are not reimbursed for extended time spent with terminally ill patients. Clearly, physician practice patterns need to change. This could be accomplished by paying doctors for longer evaluations and more extensive management time with patients.

Similarly, providers' financial incentives could be re-directed to encourage hospitals and physicians to manage and coordinate palliative care for patients. In conjunction, major health care institutions could expand palliative care units and consultative services.

It is also important for providers to identify “trigger” or “inflection” points in the course of fatal diseases that will allow them to implement palliative care sooner in the illness process than is currently the case. “Moving palliative care ‘upstream’ is promising as an approach to minimizing the burden of chronic illness and helping patients adjust to an illness while providing quality care at low costs,” says Linda Emanuel. “This is the win-win we are looking for.”²⁵

In other words, palliative care need not be reserved for those who are very close to death. Rather, it could be available soon after diagnosis so that patients can learn about and adjust to their illness early on from a team of professionals trained to administer to the social issues, psychological issues, pastoral issues, existential issues, and financial issues that are all part of whole-picture, personalized care.²⁶ This approach would allow terminally ill patients to draw on these resources and continue to function at a high level in society for an extended period of time.²⁷

One way to move palliative care upstream is to introduce a “care manager” to the process early on, says Donald Schumacher, president and CEO of the Center for Hospice and Palliative Care. The care manager walks the patient and his or her family through the disease process from diagnosis to bereavement.²⁸ He or she would serve as a constant as patients move among different care settings.

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Overcoming Barriers to Good End-of-Life Care

The “Whole Person” Assessment

One of the key messages of the conference was that people diagnosed with terminal illnesses need to be treated as whole individuals. Too often, providers focus only on a patient’s disease and fail to embrace the other needs of the entire person. An emphasis on a “whole person” assessment by an interdisciplinary team of providers is a hallmark of hospice care.²⁹ Throughout the caregiving process, providers should continually reassess and adjust the goals of care as patients’ illnesses evolve. Providers also need to coordinate care with each other as patients transition from chronic to end-of-life care.

One of the greatest challenges facing policymakers may be in crafting payment mechanisms that support the whole person assessment. As discussed earlier, current payment silos would need to be integrated into a single system to accomplish this.

Information and Education

Both health care professionals and patients harbor many misconceptions about what hospice is and how end-of-life care is administered. More education is needed for all stakeholders—including physicians, nurses, health plans, families, and patients—to emphasize that services are available from the point of a patient’s diagnosis through a family’s bereavement.

Currently, health care providers are not adequately trained in medical school or continuing education programs about key aspects of caring for the dying, including pain management, advance planning, and psychological counseling. Thus, policymakers should support efforts to train providers to better care for dying patients. Some strategies that administrators and other decision-makers can use to educate health providers include:

- ◆ administering information about end-of-life services in small amounts;
- ◆ providing guidelines in the form of template programs to help physicians navigate the end-of-life care system;

- ◆ using case managers or care coordinators to help physicians recognize the right time to introduce end-of-life care;
- ◆ holding a series of public hearings to train providers; and
- ◆ implementing regulations to affect physician practice patterns.

Advance Directives

The failure to clearly document the wishes of the terminally ill patient through advance directives, including living wills and durable powers of attorney, can impede good end-of-life care.³⁰ Health care plans and providers can improve the quality of care by encouraging individuals to participate in the health care decision-making process, particularly while patients still have the mental faculties to do so. Physicians should be adequately reimbursed for the time they spend discussing advance directives with patients. When asked, most Americans say that they would prefer to die at home, rather than hooked up to machines in a hospital.³¹

Socioeconomic Status

Evidence suggests that hospice care is used largely by upper-class and upper-middle-class individuals.³² Although some claim that the hospice-use disparity among races is shrinking, many members of minority groups retain a feeling of distrust about the health care system, including aspects of it that relate to end-of-life care. Minorities and economically disadvantaged individuals often feel that they are excluded from the health care system in America. As a result, they may not be open to the suggestion that they are better off forgoing curative care, which many have been deprived of throughout their lives.³³ Community leaders need to launch aggressive interventions—such as multi-lingual educational campaigns and outreach visits to specific neighborhoods—to resolve issues of mistrust and to educate minorities about the availability and benefits of end-of-life care.

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Key Innovations in End-of-Life Care

Throughout the country, a number of organizations have made small steps toward improving the design, delivery, and financing of end-of-life care. These innovators, which include BlueCross BlueShield of Montana's Center for Hospice and Palliative Care and Hopkins ElderPlus, may provide useful lessons to policymakers looking to reform Medicare and Medicaid.

Montana's Advanced Illness Care Coordination Program

The Montana Advanced Illness Care Coordination Program (AICCP)—a division of BlueCross BlueShield of Montana—is a system of coordinated care for patients with advanced illnesses, including most cancer diagnoses, advanced chronic lung disease, and advanced congestive heart failure. It promotes collaboration among primary care providers and other health care professionals, such as nurses and social workers, to provide comprehensive care for terminally ill patients and help them make decisions about their care at the end of life.

BlueCross BlueShield covers the care, and there is no separate charge for the service and no insurance criteria.³⁴ According to Charles Butler, vice president of government and public relations at BlueCross BlueShield of Montana, AICCP covers patients under the age of 65; it also recently began covering those who are eligible for Medicare. The program does not advocate for less aggressive care, but rather helps patients decide which type of care is most appropriate for them.

PACE

The Program for All-Inclusive Care for the Elderly (PACE) honors what most elderly indicate is their preference—to remain independent and maximize their level of physical, social, and cognitive functioning.³⁵ PACE is a community-based care model that is designed to keep frail elders in their own homes and communities rather than in hospitals or nursing homes. Through home or local care visits, a team of health care professionals provide older adults care that is comprehensive, coordinated, cost-effective, and capitated.

Financing for PACE is shared among Medicare, Medicaid, and private payers. PACE providers are at full financial risk. The model includes preventive care, primary care, acute care, nursing home care, day care, and respite care. There are no caps on service utilization, and no opportunities for cost shifting. As explained by Karen Armacost, director of Hopkins ElderPlus, end-of-life care through PACE manages risk through aggressive preventive health services, frequent clinical monitoring, and judicious allocation of resources by the interdisciplinary team.³⁶

Although nursing home care is a covered benefit under PACE, service utilization appears to be low, probably because the model provides at-home skilled nursing, caregiver support, medical and social visits, physical and occupational therapy, and pain management through prescription medications. Many PACE sites are also creating positions for pastoral care, and some programs are shifting budgets to include bereavement follow-up. In

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addition, PACE provides nontraditional Medicare benefits, such as pest control and air conditioners, to make patients' home environments more comfortable.³⁷

On Lok, the San Francisco-based prototype on which PACE is based, receives capitated payments from Medicare and Medicaid and provides managed care for enrollees who are at least 55 years old. Patients are not referred to hospice; rather, an interdisciplinary team provides comfort care and pain management for enrollees at the end of life.³⁸

Several questions about the PACE program remain:

- ◆ When should the interdisciplinary team initiate end-of-life care?
- ◆ How could the comfort level of the team providing care and discussing end-of-life issues be increased?
- ◆ What are the most necessary skills and staff positions for the team?
- ◆ How does the program accept patients' choices for ongoing care when the financial impact of that choice is known?
- ◆ Why is use of this program so limited?
- ◆ And, finally, how should PACE and hospice interact?

By initiating an active dialogue, PACE and hospice officials could find appropriate solutions to these and other challenges facing the program.³⁹

Additional Programs

Support Blue—a program associated with BlueCross BlueShield of Western New York—was designed to serve patients with chronic, life-limiting illnesses and their primary caregivers.⁴⁰

Once patients are assessed, a case manager coordinates a variety of medical, psychosocial, and spiritual services and facilitates communication among the involved parties. The program, which is designed for patients who are not yet ready for hospice, is available to all managed care members, including persons enrolled in Medicaid and Medicare managed care programs. Patients can be moved out of the program when they enter hospice or change insurance carriers. The program has been shown to be cost-effective, as it led to a reduction in emergency room visits and hospitalizations for Support Blue patients.

The Community Medical Alliance (CMA), a capitated health plan in Boston, provides comprehensive health and long-term care for people with AIDS or severe disabilities. CMA receives capitated payments from the Massachusetts Medicaid program. It provides enrollees with all Medicaid benefits, including a variety of end-of-life services.⁴¹

EverCare, a subsidiary of United HealthCare Corporation, is also a capitated Medicare managed care program. It provides preventive and primary care services to nursing homes and assisted living facilities. The capitated payment method allows providers to supply the services that individuals need without worrying if patients meet the requirements of the fee-for-service system.

The EverCare system integrates primary care and palliative services. Nurse practitioners serve as the focal point for an interdisciplinary team of caregivers. For residents at the end of life, EverCare offers pain management, hydration, comfort care, and other end-of-life services. Patients and their families who would benefit from bereavement counseling are referred to hospice.⁴²

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Next Steps for Policy and Research

Financing Mechanisms to Improve End-of-Life Care

As discussed earlier, reframing the financial incentives to support end-of-life care would improve the current system. One way to encourage early dialogue among physicians and their terminally ill patients is to ensure proper billing codes for hospital and physician reimbursements for the consultative aspects of palliative care (e.g., a palliative care diagnosis-related group (DRG) for inpatient hospital care). Provider reimbursement policies can ensure continuity of care by the same physician or physician group, so that individuals can receive care from one focused, continuous caregiver, rather than a random assortment of providers who do not have responsibility for one another or the patient.⁴³

Recent revisions to the Family Medical Leave Act (FMLA) may give individuals more flexibility to care for dying loved ones and alleviate some of the burden on informal caregivers. The FMLA entitles private, state, and local government and some federal employees to take up to 12 weeks of unpaid leave in a 12-month period for various family and medical reasons, including care of a family member with a serious health condition. While the Act allows employees to take intermittent leave, policymakers could consider building more flexibility into the law to account for the uncertainties of end-of-life care.⁴⁴

Like the Family Medical Leave Act, the National Family Caregiver Support Program also provides aid to family caregivers. The program, which was funded in 2001, offers information about available services, counseling, training, respite care, and support. Unfortunately, however, resources for

the program fall short. Increased funding for this program would help ensure that the people who bear the emotional and financial burden of care for a dying family member are cared for themselves.⁴⁵

The Role of Policymakers

Hospice costs account for only 1 percent of Medicare spending each year.⁴⁶ This does not leave Medicare officials or hospice administrators with much leverage to get the attention of policymakers. Instead, decision-makers should focus on the fact that one-quarter of Medicare's annual spending on beneficiaries age 65 or older is attributable to beneficiaries in the last year of life.⁴⁷ Even more significantly, many individuals will be disabled with their final fatal disease for an average of three years before death.⁴⁸

Given today's bleak economic climate and the uncertain prospects for Medicare's future, it may be unrealistic to count on significantly increased Medicare support for end-of-life care beyond that required to accommodate the aging population. Instead, stakeholders need to be creative and flexible in restructuring health care delivery at the end of life in order to develop less costly, more desirable alternatives.

What policymakers can do is facilitate informed dialogues by making good information available about end-of-life care. They can also make incremental reforms to the Medicare and Medicaid programs so that end-of-life care will fall more squarely under the rubric of mainstream medicine.

Despite recent growth in participation in Medicaid and Medicare hospices, relatively few beneficiaries choose to use this benefit. The Medicare and

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Medicaid programs, as well as private-sector insurance carriers, could effect change by offering alternative benefits and coverage and more broad-based educational programs. Targeted publications, advertising, and public service announcements could be used to inform patients and their families about the end-of-life care options available to them.

With many states experiencing budget shortfalls, getting financing for end-of-life care to the top of the legislative agenda is no easy task, says Carolyn Cassin, administrator at the Michigan Department of Community Health. Nevertheless, engaging state leadership is essential. While end-of-life care may not be the type of issue to cause a community-based groundswell, incremental steps can make a difference. Cassin suggests:

- ◆ Finding leadership within the state and encouraging these leaders to champion the issue at all levels;
- ◆ Raising critical end-of-life issues and encouraging funding for programs;
- ◆ Broadening the public debate; and
- ◆ Sharing anecdotes of individuals faced with making decisions about end-of-life care with policymakers and consumers.

“As a society, we do not have a large experience with death,” says Samuel Warburton. Most people experience the death of family members fairly infrequently, and each death takes place under different circumstances; there is no means by which we can measure or compare one experience against another. Thus, the public needs to be informed that better options are available.

More Research Is Needed

In its May 2002 report to Congress, MedPAC concluded that:

Better information is needed about the services patients need and use, and about differences in use of services among hospice patients. Research on these topics is needed to lay a foundation for a payment system that accounts for differences in the resources needed to care for patients. It also will help improve payments for costly patients, whether in concert with the existing payment policy or with a case-mix adjusted payment system.⁴⁹

Relatively little research has been conducted on the financing and delivery of end-of-life care. As MedPAC noted, “policymakers need more information on the care patients need, the services they receive, and differences among types of patients.... These questions cannot be answered without research.”⁵⁰ Researchers should consider developing projects that would substantiate anecdotal evidence that hospice and palliative care services are less costly than mainstream curative medical care.

Potential future research topics might include:

- ◆ An analysis of whether a case-mix adjustment payment system is feasible;⁵¹
- ◆ Research on outlier policies, including an examination of the threshold and cost-sharing for home health outlier payments;⁵²
- ◆ Cost analyses on informal caregiver support;⁵³

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- ◆ Analyses using the Medicare Current Beneficiary Survey (and other national databases) relative to end-of-life health care expenditures;
- ◆ Analyses of treatment costs for hospice enrollees of a certain type (e.g., cancer patients) versus non-hospice patients with the same disease;
- ◆ Analyses of variation in hospice penetration across the country, as well as variation in hospice costs;
- ◆ Analyses of varying lifespans and related costs (How do you capture the cost of a fatal illness at an arbitrary point in time ahead of death, or from the onset of a certain degree of disability or severity of illness?);
- ◆ Demonstration projects analyzing innovative funding mechanisms, including consolidation of multiple funding sources;
- ◆ Demonstration projects analyzing alternatives to the six-month hospice eligibility requirement;
- ◆ Demonstration projects analyzing geographic variation in Medicare spending during the last six months of life;⁵⁴
- ◆ Identification of best end-of-life practices in the field and the development of practice guidelines;⁵⁵ and
- ◆ Descriptive analyses of hospice patient satisfaction data versus mainstream medicine.

Securing more private and public research dollars will be necessary to fill the information gaps that now exist—figuring out what works and what it costs. Building on facts rather than anecdotes will result in better policy.

Endnotes

1. On February 6, 2002, The Robert Wood Johnson Foundation's Changes in Health Care Financing and Organization (HCFO) Initiative and Last Acts® Campaign sponsored a conference in Washington, D.C., titled Financing End-of-Life Care: Challenges for An Aging Population.
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3. Hogan, C. et al. "Medicare Beneficiaries' Costs of Care in the Last Year of Life," *Health Affairs*, Vol. 20, No. 4, July/August 2001, pp. 188-95.
4. Emanuel, L. "Setting the Context: What Do We Know About End-Of-Life Care?" Draft paper presented at Financing End-of-Life Care: Challenges for An Aging Population.
5. Harris Interactive, *A Study about End of Life Care*. Prepared for The National Hospice and Palliative Care Organization, January 28, 2002.
6. Moon, M. and C. Boccuti. "Medicare and End-of-Life Care." Draft paper presented at Financing End-of-Life Care: Challenges for An Aging Population.
7. Miller, G. et al. Delivering Quality Care and Cost-Effectiveness at the End of Life. Commissioned by the National Hospice and Palliative Care Organization, February 2002, p. 14; Lynn, J. and A. O'Mara. "Reliable, High-Quality, Efficient End-of-Life Care for Cancer Patients: Economic Issues and Barriers," *Improving Palliative Care for Cancer*, Institute of Medicine, 2001, pp. 74-75.
8. Testimony of William J. Scanlon before the Special Committee on Aging, U.S. Senate, "More Beneficiaries Use Hospice; Many Factors Contribute to Shorter Periods of Use," United States General Accounting Office, September 18, 2000.
9. Matherlee, K. "Managing Advanced Illness: A Quality and Cost Challenge to Medicare, Medicaid, and Private Insurers." Issue Brief, National Health Policy Forum, No. 779, June 20, 2002.
10. Report to the Congress, Medicare Beneficiaries' Access to Hospice, Medicare Payment Advisory Commission, May 2002.
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12. Meeting discussion, Financing End-of-Life Care: Challenges for An Aging Population, sponsored by The Robert Wood Johnson Foundation's Changes in Health Care Financing and Organization (HCFO) Initiative and Last Acts Campaign, February 6, 2002.
13. Wilkinson, A. et al. "Innovative Models of Financing and Delivery of End of Life Care." Draft paper presented at Financing End-of-Life Care: Challenges for An Aging Population; Moon, M. and C. Boccuti "Medicare and End-of-Life Care." Draft paper presented at Financing End-of-Life Care: Challenges for An Aging Population.
14. Emanuel, L. "Setting the Context: What Do We Know About End-Of-Life Care?" Draft paper presented at Financing End-of-Life Care: Challenges for An Aging Population.
15. Lynn, J. Meeting discussion, Financing End-of-Life Care: Challenges for An Aging Population, sponsored by The Robert Wood Johnson Foundation's Changes in Health Care Financing and Organization (HCFO) Initiative and Last Acts Campaign, February 6, 2002.
16. Matherlee, K. "Managing Advanced Illness: A Quality and Cost Challenge to Medicare, Medicaid, and Private Insurers." Issue Brief, National Health Policy Forum, No. 779, June 20, 2002.
17. Cassel, C.K. et al. "Perceptions of Barriers to High-Quality Palliative Care in Hospitals." *Health Affairs*, Vol. 19, No. 5, September/October 2002, pp. 166-72.
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19. Joshua M. Wiener. Meeting discussion, Financing End-of-Life Care: Challenges for An Aging Population, sponsored by The Robert Wood Johnson Foundation's Changes in Health Care Financing and Organization (HCFO) Initiative and Last Acts Campaign, February 6, 2002.
20. Tilly, J. and J. Wiener. Medicaid and End-of-Life Care, Spring 2001, p. 9.
21. Tilly, J. and J. Wiener. Medicaid and End-of-Life Care, Spring 2001, p. 15.
22. Alliance for Health Reform, "How Do We Pay For...Care at the End of Life?" December 2001.
23. New End-of-Life Benefits Models in Blue Cross & Blue Shield Plans. Distributed by

- Last Acts Financing Committee, January 2002.
24. Tilly, J. and J. Wiener. Medicaid and End-of-Life Care, Spring 2001, p. 23.
 25. Meeting discussion, Financing End-of-Life Care: Challenges for An Aging Population, sponsored by The Robert Wood Johnson Foundation's Changes in Health Care Financing and Organization (HCFO) Initiative and Last Acts Campaign, February 6, 2002.
 26. Lamberg, L. "Palliative Care' Means 'Active Care.' It Aims to Improve Quality of Life," *JAMA*, Vol. 288 No. 8, August 28, 2002.
 27. Miller, G. et al., Delivering Quality Care and Cost-Effectiveness at the End of Life, Commissioned by the National Hospice and Palliative Care Organization, February 2002, pp. 16-18.
 28. "Most Americans believe that terminal patients would benefit from consultations with end-of-life care specialists." "Most Americans who believe that terminally ill patients would benefit from consultation believe that consultation should occur when patients are given a life-limiting prognosis of two years or less." Harris Interactive, A Study about End of Life Care, Prepared for The National Hospice and Palliative Care Organization, January 28, 2002.
 29. Emanuel, L. "Setting the Context: What Do We Know About End-Of-Life Care?" Draft paper presented at Financing End-of-Life Care: Challenges for An Aging Population.
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 31. Harris Interactive, A Study about End of Life Care. Prepared for The National Hospice and Palliative Care Organization, January 28, 2002.
 32. Emanuel, L. Meeting discussion, Financing End-of-Life Care: Challenges for An Aging Population, sponsored by The Robert Wood Johnson Foundation's Changes in Health Care Financing and Organization (HCFO) Initiative and Last Acts Campaign, February 6, 2002.
 33. Meeting discussion, Financing End-of-Life Care: Challenges for An Aging Population, sponsored by The Robert Wood Johnson Foundation's Changes in Health Care Financing and Organization (HCFO) Initiative and Last Acts Campaign, February 6, 2002; Report to the Congress, Medicare Beneficiaries' Access to Hospice, Medicare Payment Advisory Commission, May 2002.
 34. *New End-of-Life Benefits Models in Blue Cross & Blue Shield Plans*, Distributed by Last Acts Financing Committee, January 2002.
 35. Armacost, K. Presentation, Financing End-of-Life Care: Challenges for An Aging Population.
 36. Ibid.
 37. Ibid.
 38. Tilly, J. and J. Wiener. Medicaid and End-of-Life Care, Spring 2001, pp. 17-19.
 39. Armacost, K. Presentation, Financing End-of-Life Care: Challenges for An Aging Population.
 40. *New End-of-Life Benefits Models in Blue Cross & Blue Shield Plans*, Distributed by Last Acts Financing Committee, January 2002.
 41. Tilly, J. and J. Wiener. Medicaid and End-of-Life Care, Spring 2001, pp. 16-17.
 42. Tilly, J. and J. Wiener. Medicaid and End-of-Life Care, Spring 2001, pp. 19-20.
 43. Lynn, J. and A. O'Mara. "Reliable, High-Quality, Efficient End-of-Life Care for Cancer Patients: Economic Issues and Barriers," *Improving Palliative Care for Cancer*, Institute of Medicine, 2001, pp. 87-88.
 44. On September 23, 2002, California Governor Gray Davis signed legislation that will allow employees to take up to six weeks of partially paid leave beginning in 2004. California is the first state to authorize paid family and medical leave. The paid leave will be funded by an increase in employee contributions to the State Disability Insurance Fund.

45. On September 26, 2002, HHS Secretary Tommy Thompson announced the award of \$7 million in grants through the National Family Caregiver Support Program to provide technical assistance, resource materials and training to the aging and caregiver communities nationwide.
46. Moon, M. and C. Boccuti. "Medicare and End-of-Life Care." Draft paper presented at Financing End-of-Life Care: Challenges for An Aging Population.
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About the Program

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