

Supporting Family Caregivers



1.5

HOURS

Continuing Education

Community and In-Home Models

PACE and state-based payment for in-home supportive services.

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Providing and coordinating cost-effective, comprehensive care for older adults who want to remain in the community but need long-term assistance are serious challenges for families and professionals. Addressing these issues will require a redesign of the care delivery system. This article describes two successful models for working with older adults in the community: the Program of All-Inclusive Care for the Elderly (PACE) and a state-financed approach that covers in-home supportive services.

PACE

PACE serves 15,000 people in 22 states and integrates social and medical services through a combination of adult day health care and home care (see www.npaonline.org). Participants must be age 55 or older; the average age is 80 years. Although they have to meet the criteria for nursing home admission, PACE participants are able to live safely in the community. PACE covers all primary, acute, and long-term care services, including physicians' services, hospitalization, nursing-home care, therapies, prescription drugs, and equipment.¹ (With the addition of 18 more PACE programs in rural areas by the end of 2008, older adults in 27 states will have access to PACE.)

History. On Lok Senior Health Services in San Francisco was the prototype for PACE. On Lok originated in the early 1970s as a way to fill the gap in long-term care options for older adults, especially immigrants who were Italian, Filipino, and Chinese.^{2,3}

Beginning in the mid-1980s, the Centers for Medicare and Medicaid Services (then known as the Health Care Financing Administration) initiated demonstration projects to test the PACE model at 10 sites.⁴ The findings of these demon-



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stration projects indicated that PACE was associated with decreased home visits by nurses, inpatient hospital admissions, inpatient hospital days, and nursing-home days. In addition, people enrolled in PACE demonstrated improved quality of life, satisfaction with care, and functional status, and they lived longer and spent more days in the community than those not participating in PACE.⁵ The quality and satisfaction with the PACE model justified further expansion and testing at eight sites. As a result of the evidence from these demonstration projects, Congress authorized PACE under Medicare as part of the Balanced Budget Act of 1997.

Scope of the program. In the PACE model, an interdisciplinary team provides both health care and social services. Components of PACE include primary care, specialty care, adult day care, home care, hospital care, nursing-home care, medication oversight, and transportation to medical appointments. The primary site of delivery for many of the services is an adult day health care center. The inter-

disciplinary team at each PACE center includes at least one physician, nurse, social worker, dietitian, occupational therapist, physical therapist, and recreational therapist. Complementing these professionals are home care workers and other ancillary personnel, such as drivers.

The interdisciplinary team assesses each participant before enrollment and at least every six months. With the participant and family, the team creates a care plan that encompasses both medical and social care. This could include therapy and maintenance care at home or at the PACE center, a medication-management plan, preventive health care, nutrition services, and respite care for family caregivers.

The PACE financing model addresses the needs of elderly people and their families, as well as economic issues. It combines payments from Medicare, Medicaid, and private-pay sources (for participants not eligible for Medicaid) into one flat-rate payment that provides for the entire range of individualized long-term, primary, and acute care and services. This capitated reimbursement mechanism also allows PACE programs to provide participants with services that might not otherwise be covered by Medicaid or Medicare.⁶

Support for family caregivers is in the form of direct care, care coordination, and case management. The PACE program may provide respite care and counseling for family members and offer increased home care hours or attendance at the adult day health care center, if needed.⁷ In addition, some PACE sites measure caregiver strain and educate family members on ways to handle it better.

In essence, the ultimate test of care coordination and care delivery systems is when a patient is discharged from the hospital on Friday at 5:00 PM. Not only does the PACE model pass this test, it also recognizes the needs of both the patient and caregiver—the family unit. If they need transportation home from the hospital, PACE provides it. If equipment or medication supervision is needed in the home, someone from PACE addresses these needs, probably that night. On Saturday, care services will be available in the home or at the PACE center. In addition, PACE can relieve the caregiver of the burden of preparing meals, if that is needed.

Outcomes. The PACE model serves as a “health care home” for enrollees—that is, a primary care site where an individual’s health care is coordi-

nated. Multidisciplinary team performance, the availability of diverse services, and reliance on staff physicians who share the program’s values have resulted in improved risk-adjusted patient outcomes in death rate, functional status, and overall health.^{8,9}

One measure of participant satisfaction is the disenrollment (dropout) rate; for PACE, it is only about 7% a year. According to Shawn Bloom, president and chief executive officer of the National PACE Association, this disenrollment figure includes individuals who move out of the service area or discontinue for reasons not associated with dissatisfaction.

PACE serves many frail older participants who have no family caregivers and those with caregivers in groups at high risk for burnout, including those who are not spouses and those over the age of 75. A recent study found no increased risks for institutionalization among these participants.¹⁰ The researchers concluded

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that the program’s multidisciplinary approach to caregiver and patient support may be meeting the needs of these vulnerable populations, which if not addressed may lead to nursing home admission.

POTENTIAL BEYOND PACE

The PACE sites throughout the country are living laboratories for the study of family caregiving and the economics of care. Health care home payments, care coordination payments, transitional care payments—all are bundled together in the capitated PACE model.

The PACE model is a good source for preliminary data on how well a community-based model

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can work. But federal and state rules make the PACE program highly organized and regulated. Communities and providers may want to adapt it to meet their local needs.

One less restrictive model based on PACE is the Wisconsin Partnership Program. A study found that the highly regulated PACE model was significantly more effective than this more flexible program in controlling hospital and ED use for its enrollees.¹¹ One reason for this may be that PACE is an integrated system of care staffed by physicians who embrace PACE's values and interdisciplinary approach. Changing practice styles to provide better chronic care management is difficult but seems essential.

How can large health plans and older adults who are treated mainly by physicians and without a coordinated set of companion services achieve the outcomes seen with a fully organized system that includes both medical and nonmedical services? Discussions about this issue are beginning with the concept of a "health care home" and transitional care programs that emphasize posthospital discharge care and care coordination.¹² Such efforts, although specifically focused on care for the patient, indirectly support the caregiver.

PAYING FAMILY CAREGIVERS WITH PUBLIC FUNDS

At one time, the policies of Medicare and other payors did not allow for payment of family caregivers, but would pay unrelated caregivers. That approach is starting to change.

California model. California's In-Home Supportive Services Program, a part of Medi-Cal, the state's Medicaid program, is a consumer-directed care model in which the individual receives cash to employ the caregivers of his or her choosing, including family caregivers. This concept is referred to as "money follows the person." The model allows some compensation to ease the economic burden on family caregivers.

This consumer-directed model outperformed professional management models for the delivery of supportive services to older persons and those with disabilities on several measures, including client satisfaction and quality of life. The presence of a paid family caregiver was associated with more positive outcomes.^{13, 14}

The Medi-Cal model makes it easier for older adults and others to receive culturally appropriate care. They can engage family members who, by definition, are from the same ethnic and cultural

TAKE-HOME MESSAGES

- The health care delivery and financing systems need to be redesigned to help older adults with multiple clinical, functional, and social issues best maintain their well-being with appropriate use of preventive, acute, and rehabilitative services.
- Coordinated, simplified, and comprehensive care obtained through a "health care home" is both possible and cost-effective for helping older adults and their family caregivers manage health conditions at home, including acute episodes, and improves their quality of life.
- Culturally appropriate and effective care is best achieved with a community base rather than the typical institutional focus.

background. This model is being increasingly used around the country.

Policy issues. An implicit policy issue with this model is related to the use of public funds to pay family caregivers. This shift addresses some fundamental questions in the care of older adults and of people with disabilities: Is caregiving a family responsibility? At what point does family caregiving become an economic issue? Is it possible to assess and quantify both the services themselves and their value to the family?

Supporting family systems is a core principle of the social work and nursing professions that is also acknowledged by the general public. Because public dollars are often involved, it is important to articulate an economic case for the value and cost-effectiveness of providing family support. If the business case can be made for a model like PACE or California's In-Home Supportive Services Program, the result may be a redesigned, cost-effective system that emphasizes care coordination and works seamlessly through transitions in care for the benefit of both older adults and family caregivers. ▼

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