GAO

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END-OF-LIFE CARE

Key Components Provided by Programs in Four States

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Why GAO Did This Study

Approximately 28 percent of all Medicare spending in 1999 was used to provide care for beneficiaries in the last year of their lives. The Medicare hospice benefit is specifically designed for end-of-life care but is an elected benefit for individuals who have a terminal diagnosis with a prognosis of 6 months or less if the disease runs its normal course. GAO was asked to identify examples of programs that provide key components of end-of-life care. Specifically, GAO (1) identified key components of end-of-life care, (2) identified and described how certain programs incorporate key components of end-of-life care, and (3) described the challenges program providers have identified to delivering the key components of end-of-life care. To identify the key components of end-of-life care, GAO relied on studies by the Institute of Medicine (IOM) and the Agency for Healthcare Research and Quality (AHRQ). To identify and describe programs that implement these key components and describe the challenges providers of these programs face, GAO conducted site visits to four states, Arizona, Florida, Oregon, and Wisconsin, that, in addition to other criteria, demonstrated a high use of end-of-life services. We interviewed officials of federal, state, and private programs in these four states that provide care to individuals nearing the end of life.

What GAO Found

The IOM and AHRQ studies identified the following key components in providing care to individuals nearing the end of life: care management to coordinate and facilitate service delivery; supportive services, such as transportation, provided to individuals residing in noninstitutional settings; pain and symptom management; family and caregiver support such as respite care; communication among the individuals, families, and program staff; and assistance with advance care planning to aid individuals with making decisions about their future care.

The programs GAO identified in the four states incorporate key components of end-of-life care when delivering services to individuals nearing the end of life. These programs use care management, either through a case manager or an interdisciplinary care team of health care professionals, to ensure continuity of care and the delivery of appropriate services. The programs also provide supportive services, such as personal care services or meal delivery, to assist individuals in their homes. Pain and symptom management is provided by these programs to treat pain and other symptoms of an individual who is seriously ill. These programs provide family and caregiver support through services that alleviate demands on the caregiver and by providing bereavement support for family members. The programs foster communication with individuals and family members to plan care that reflects each individual's choices. In addition, these programs use tools such as electronic medical records to facilitate communication among staff members. The programs GAO identified initiate and encourage advance care planning for the end of life and assist individuals with making decisions about future medical care, such as completing advance directives and identifying health care proxies, that is, those who can make health care decisions on behalf of the individual.

Providers of the programs GAO identified described challenges they encounter to delivering some of the key components of end-of-life care. Providers described difficulties delivering supportive services and family and caregiver supports to rural residents because of travel distances, fewer community-based service options, and an inability to hire adequate numbers of staff in rural areas. Providers also stated that, in their experience, physician training and practices can inhibit the provision of pain and symptom management and advance care planning to individuals nearing the end of life. A recent article published in a medical journal GAO reviewed identified similar issues with physician training and practices.

The Centers for Medicare & Medicaid Services (CMS), the agency that administers Medicare and Medicaid, commented that the report is a useful description of diverse provider types that deliver services to persons coming to the end of life. CMS noted that the report is especially helpful as a time approaches when more Americans will be living with serious and eventually fatal chronic conditions.

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United States Government Accountability Office

Contents

Abbreviations

ABMS	American Board of Medical Specialties
AHRQ	Agency for Healthcare Research and Quality
ALTCS	Arizona Long Term Care System
CMS	Centers for Medicare & Medicaid Services
COPD	chronic obstructive pulmonary disease
IOM	Institute of Medicine
NAHC	National Association for Home Care and Hospice
NEJM	*New England Journal of Medicine*
NHPCO	National Hospice and Palliative Care Organization
PACE	Program of All-Inclusive Care for the Elderly
POLST	Physician Orders for Life-Sustaining Treatment
WPP	Wisconsin Partnership Program

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Accountability * Integrity * Reliability

United States Government Accountability Office
Washington, DC 20548

December 14, 2007

The Honorable Ron Wyden
United States Senate

Dear Senator Wyden:

In 1999, approximately 28 percent of all Medicare spending was used to provide care for beneficiaries in the last year of their lives.[1] A large percentage of this spending was for institutional services such as hospital inpatient or nursing home care; for example, slightly more than 58 percent of this spending was for hospital inpatient services. In that same year, approximately 1.5 million individuals over age 65 resided in nursing homes. Sixty-two percent of these individuals had their nursing home care paid for by Medicaid and about 16 percent had their care paid for by Medicare.[2,3] However, there are alternatives to institution-based end-of-life care, such as home and community-based services. In 2005, the Administrator of the Centers for Medicare & Medicaid Services (CMS), the federal agency that administers Medicare and Medicaid, testified that providing home and community-based services, such as personal care services,[4] can be a cost-effective way to provide end-of-life care while increasing personal autonomy and allowing individuals to live in their homes, surrounded by friends and family.[5]

Advances in treating diseases have lengthened the life expectancy of Americans, and chronic conditions such as heart failure, diabetes, or kidney failure are no longer immediately fatal and can be treated or managed with medication. As a result, more than 80 percent of Americans

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[1]Medicare is the federal health care program for elderly and certain disabled individuals.

[2]Medicaid is the joint federal-state program that provides health coverage for certain low-income individuals. Medicaid also pays for long-term care services, including nursing home care.

[3]Medicare covers some skilled nursing care following a covered hospital stay.

[4]Personal care services can be provided in the home and assist individuals with activities of daily living, such as bathing, dressing, or eating.

[5]Testimony by Mark B. McClellan, MD, PhD, Administrator of CMS, before the Subcommittee on Health, House Committee on Energy and Commerce on April 27, 2005.

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lived past age 65 in 2000; however, many individuals live their last years of life with chronic conditions. For example, according to the 2003 Medicare Current Beneficiary Survey, 21 percent of beneficiaries have had a diagnosis of diabetes, 5 percent have had a diagnosis of Alzheimer's disease, and 15 percent have had a diagnosis of pulmonary disease, such as chronic obstructive pulmonary disease (COPD). In addition, 73 percent of beneficiaries reported that they had two or more chronic conditions. Medicare beneficiaries with chronic health conditions use many health care resources. Ninety percent of Medicare beneficiaries over age 65 live with a chronic condition in the year before death.

Medicare has a program that is specifically designed for end-of-life care, the hospice benefit. The hospice benefit is designed to provide comfort and pain relief and emotional and spiritual support to individuals with a terminal illness, generally in a home setting. Medicare hospice services include, for example, nursing care, counseling, and homemaker services, as well as drugs and medical supplies. However, not all individuals nearing the end of life may qualify for or elect to receive care under this benefit. To be eligible for the benefit, a physician must certify an individual as having a life expectancy of 6 months or less if his or her illness runs its normal course. Physicians certifying patients for hospice are expected to use their best clinical judgment regarding the normal course of the individual's illness. However, the course of many conditions, such as COPD, is often uncertain, making it difficult for physicians to predict accurately the life expectancy of individuals with these conditions and, therefore, refer them to hospice. In addition, a beneficiary who elects hospice must waive Medicare coverage for curative care related to the terminal illness for the period the election is in effect.[6] Some individuals are reluctant to forgo curative care for their terminal illness and, therefore, do not elect hospice.

You are interested in health care services delivered to individuals who are nearing the end of life and asked us to identify examples of programs, other than hospice, that provide key components of end-of-life care. In this report, we (1) identify key components of end-of-life care, (2) identify and describe how certain programs incorporate key components of end-of-life care, and (3) describe the challenges program providers have identified to delivering the key components of end-of-life care.

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[6]Curative care is care intended to overcome a disease and promote recovery. Under the hospice benefit, the beneficiary retains Medicare coverage for services to treat conditions other than the terminal illness or related conditions.

To identify key components of end-of-life care, we interviewed officials from CMS and 10 national independent and academic researchers in end-of-life and long-term care. In addition, we interviewed officials from the National Hospice and Palliative Care Organization (NHPCO) and the National Association for Home Care and Hospice (NAHC), industry organizations that represent home care agencies, hospices, and palliative care providers. Based on these interviews, we identified and relied primarily on two extensive studies to identify the key components of end-of-life care: a 1997 Institute of Medicine (IOM) study and a 2004 study published by the Agency for Healthcare Research and Quality (AHRQ).[7,8] The IOM study identified factors that promote high-quality care for individuals near the end of life. The report was prepared by an IOM-appointed committee that included health care professionals and researchers with expertise in geriatrics, end-of-life care, chronic illness and disability, pain management, and long-term care. The committee prepared this report with the objective of stimulating discussion, encouraging consensus on how care for those approaching death can be improved, and encouraging action to implement that consensus. The AHRQ report is a study on the state of the science regarding end-of-life care. It includes a comprehensive review of the literature that addresses the effectiveness of specific health care interventions for improving outcomes in individuals at the end of life. In preparing its report, AHRQ reviewed a total of 5,165 abstracts applicable to the report's key questions that were published in the English language, appeared in journals from 1990 through 2004, involved human subjects, and did not include individual case reports. The AHRQ report was peer reviewed by a multidisciplinary technical expert panel that included leading scientists and clinicians in nursing, gerontology, and palliative medicine and others with a broad knowledge of relevant research and policy issues.

To identify the programs that deliver key components of end-of-life care and describe how they incorporate these key components, we first interviewed the officials from CMS, NHPCO, and NAHC and the 10 national independent and academic researchers in end-of-life and long-

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[7]Institute of Medicine, Committee on Care at the End of Life, *Approaching Death: Improving Care at the End of Life* (Washington, D.C.: National Academy Press, 1997).

[8]K. Lorenz et al., *End-of-Life Care and Outcomes*, Evidence Report/Technology Assessment No. 110, AHRQ Publication No. 05-E004-2 (Rockville, Md.: Agency for Healthcare Research and Quality, December 2004). Prepared by the Southern California Evidence-based Practice Center, under contract No. 290-02-0003.

term care. We also used 2001 data from the U.S. Census Bureau to identify states that had a high percentage of population age 65 and over. We reviewed 2003 data from the National Center for Health Care Statistics and 2000 through 2003 data from *The Dartmouth Atlas of Health Care* to identify states that had low health care service utilization as a proxy for higher-than-average use of care management.[9] In addition, we examined fiscal year 2004 Medicaid data on states' spending for certain home and community-based services. We reviewed data on the utilization of Medicare hospice services at the end of life from a study published in 2002 as a proxy for individuals who use noninstitutional services for end-of-life care. Using information from our interviews and these data, we identified 14 states that meet at least one of the following criteria: a high proportion of individuals over age 65, low health care service utilization, a high proportion of Medicaid spending for home and community-based services relative to spending for institutional services, or a high proportion of individuals who use hospice services at the end of life. From the 14 states we identified, we selected 4 states, Arizona, Florida, Oregon, and Wisconsin, that are geographically diverse and have at least one state or local program that provides care to individuals nearing the end of life. We identified programs in these states that provide care to individuals nearing the end of life and interviewed representatives of providers of these programs: the Program of All-Inclusive Care for the Elderly (PACE), the Wisconsin Partnership Program (WPP), the Medicaid Arizona Long Term Care System (ALTCS), and palliative care programs. To describe how these programs incorporate key components of end-of-life care, we conducted site visits to interview representatives of PACE providers in Florida, Oregon, and Wisconsin; representatives of three providers of WPP;[10] state officials from the ALTCS program; and representatives of at least 2 palliative care programs in each of the four states for a total of 12 palliative care programs.[11]

To describe the challenges these programs encounter in providing the key components of end-of-life care, we conducted site visits to interview representatives of PACE providers in Florida, Oregon, and Wisconsin;

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[9]Low health care service utilization may result from use of coordinated care as well as from other factors such as underservice.

[10]One of the WPP providers is also a PACE provider.

[11]Four of these programs are administered by hospitals, two are administered by health care systems, and six are administered by hospices. The palliative care programs administered by these hospices are separate from the hospice program.

representatives of three providers of WPP; state officials from the ALTCS program; and representatives of at least 2 palliative care programs in each of the four states for a total of 12 palliative care programs. We performed our work from June 2005 through August 2007 in accordance with generally accepted government auditing standards.

Results in Brief

The IOM and AHRQ studies identified six key components in providing care at the end of life. These were care management to coordinate and facilitate service delivery; supportive services to assist individuals residing in noninstitutional settings; pain and symptom management; family and caregiver support; communication among the individuals, families, and program staff; and assistance with advance care planning to aid individuals with making decisions about their future care.

The programs we identified in four states that incorporate these key components of end-of-life care when delivering services to individuals nearing the end of life are PACE, WPP, ALTCS, and palliative care programs. These programs use care management, either through a case manager or an interdisciplinary care team of providers, to ensure continuity of care and the delivery of appropriate services; supportive services such as personal care services to assist individuals with daily activities or transportation to access medical care; pain and symptom management to improve quality of life and assist with transitions at the end of life; family and caregiver support through services that alleviate demands on the caregiver and provide bereavement support; communication to assist individuals and their families with developing care plans that reflect their choices; and advance care planning to assist individuals with decision making at the end of life.

Providers we interviewed in the four states found challenges to delivering some key components of end-of-life care. Representatives of the providers described difficulties providing supportive services and family and caregiver support to rural residents because of travel distances, fewer community-based service options, and an inability to hire adequate numbers of staff in rural areas. Provider representatives also stated that, in their experience, physician training and practices can inhibit the provision of pain and symptom management and advance care planning to individuals nearing the end of life. A recent article published in a medical journal we reviewed identified similar issues with physician training and practices.

In commenting on a draft of this report, CMS stated that the report is a useful description of a diverse set of provider types in very different settings providing services to persons coming to the end of life, and is especially helpful as a time approaches when more Americans will be living with serious and eventually fatal chronic conditions. CMS noted that it was useful that our report included individuals living with serious chronic conditions who might live for some years.

Background

PACE integrates Medicare and Medicaid financing to provide comprehensive delivery of those programs' services to individuals age 55 and older who have been certified as eligible for nursing home care by a state under Medicaid. PACE providers are, or are a separate part of, government entities or are not-for-profit private or public entities that provide PACE services to eligible individuals. PACE services include, but are not limited to, all Medicare services and all Medicaid services as specified in the state plan.[12] Adult day care, medical treatment, home health and personal care, prescription drugs, social services, restorative therapies, respite care,[13] and hospital and nursing home care when necessary are all required services under PACE. For most individuals, the comprehensive services offered by PACE allow them to live in their homes. CMS requires that each PACE provider operate an adult day center for its beneficiaries.

WPP is a state-sponsored program that integrates Medicare and Medicaid financing to provide comprehensive delivery of those programs' services to individuals age 55 and older and individuals age 18 and older with physical disabilities who have been certified by Wisconsin as eligible for nursing home care. To deliver WPP services, the state contracts with organizations to provide eligible individuals with primary, acute, and long-term care services; prescription drugs; rehabilitation services and physical therapy; adult day care; nursing home care; durable medical equipment and supplies; and other services such as meal delivery and transportation to medical appointments. The comprehensive services provided by WPP are intended to allow individuals to live in the setting of their choice.

[12]Although the PACE benefit package must include Medicare covered services, under Medicare regulations only PACE enrollees who are eligible for Medicare must be furnished Medicare services.

[13]Respite care is services that provide temporary relief from tasks associated with caring for individuals who are ill.

While similar to PACE, WPP does not require that providers operate an adult day center.

ALTCS, the long-term care division of the Arizona Medicaid program, serves individuals who are age 65 and over, blind, or disabled and who need ongoing services at a nursing home level of care. Arizona provides all its Medicaid services through a Medicaid waiver, which allows some flexibility in the design and administration of the program.[14] In Arizona, ALTCS contracts with providers to deliver acute medical care services, institutional care, hospice, behavioral health services, home health, homemaker services, personal care, respite care, transportation, adult day care, and home delivered meals. Many ALTCS participants are able to live in their own homes or in assisted living facility and receive in-home services.

Palliative care programs are operated by a variety of health care entities, including hospitals, health care systems, and hospices. These programs generally do not receive federal or state funding and may rely on private grants or charitable support. Palliative care programs are designed to improve the quality of a seriously ill individual's life and support the individual and his or her family during and after treatment. Services provided by palliative care programs vary and may include pain and symptom management, assistance with planning for additional services, and psychosocial and spiritual support and can be provided in conjunction with curative care.

Key Components of End-of-Life Care

The IOM and AHRQ studies identified the following key components in providing care to individuals nearing the end of life: care management; supportive services for individuals; pain and symptom management; family and caregiver support; communication among the individuals, families, and program staff; and assistance with advance care planning. Care management, also referred to as case management, interdisciplinary care, or care coordination, is the coordination and facilitation of service delivery and can be provided by a team or a single manager. Supportive services include personal care services, home delivered meals,

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[14]Under section 1115 of the Social Security Act, CMS has authority to waive certain statutory requirements of the Medicaid program for states to engage in experimental, pilot, or demonstration projects that promote Medicaid program objectives. While many states choose to operate limited waiver programs for targeted populations, Arizona has chosen to operate its entire Medicaid program under a demonstration waiver.

transportation to medical appointments, and other services that assist individuals who reside in noninstitutional settings. Pain and symptom management is pharmacological and nonpharmacological therapies, such as massage therapy, to treat pain and other symptoms of an individual who is seriously ill. Family and caregiver support are services that provide assistance to those caring for an individual nearing the end of life in his or her home and can include respite care and bereavement counseling. Communication among individuals, families, and program staff includes discussions regarding end-of-life issues with individuals and their family members and the use of various tools to foster communication among program staff. Advance care planning is the process by which individuals make decisions about their future care and may include the completion of written documents, such as advance directives.[15]

Specifically, IOM reported that for individuals nearing the end of life, care systems should ensure that the following are provided: interdisciplinary care management; home care or personal care services, which we refer to as supportive services; pain and symptom management; supportive care for caregivers and family through services such as respite care or housekeeping services; and communication. The IOM report also identified advance care planning as a key component of end-of-life care. The IOM report recommended that people nearing the end of life should receive supportive services managed by those involved in their care and that health care organizations should facilitate advance care planning. In addition, the IOM report recommended that health care professionals improve care for individuals nearing the end of life by providing pain and symptom management.

The AHRQ report focused on identifying outcomes that can indicate the quality of the end-of-life experience and identifying the patient, family, and health care system factors that are associated with better or worse outcomes at the end of life. The AHRQ report identified continuity of health care, such as that provided through care management; supportive services, such as home care services; pain and symptom management; support for families and caregivers; and effective communication among program staff, which could include improved medical record documentation, as core components of end-of-life care.

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[15]Advance directives are documents that communicate an individual's wishes about end-of-life care (for example, preferences about the use of medical interventions such as a feeding tube or breathing machine) in the event that the individual is unable to communicate, and include living wills and medical powers of attorney.

Programs Incorporate Key Components of End-of-Life Care

The programs we identified in four states that incorporate key components of end-of-life care described in the IOM and AHRQ reports are PACE, WPP, ALTCS, and palliative care programs. These programs use care management to ensure continuity of care and supportive services, such as personal care services, to assist individuals nearing the end of life. These programs also integrate pain and symptom management into their services; provide family and caregiver support; foster communication among the individuals, families, and program staff; and initiate or encourage advance care planning.

Programs Use Care Management to Ensure Continuity of Care

Care management is used by all of the programs we identified to ensure continuity of care for individuals nearing the end of life. Most of these programs provide care management through interdisciplinary care teams. The interdisciplinary care teams of PACE providers include a primary care physician, nurse, social worker, physical therapist, occupational therapist, recreational therapist or activity coordinator, dietitian, PACE adult day center manager, health care aides, and transportation providers. PACE beneficiaries attend a PACE adult day center where they receive services from the interdisciplinary care team. The WPP providers use an interdisciplinary care team approach similar to PACE, although the teams are generally smaller. Representatives of two WPP providers we interviewed stated that care management reduces hospitalizations. Representatives of one of these providers stated that care management ensures that individuals admitted to a hospital are discharged to an appropriate setting to avoid unnecessary readmission. Representatives of the second WPP provider stated that care management improves the medical care of individuals by providing physicians with an accurate picture of individuals' health status and assisting individuals with accessing physicians in a timely manner. Representatives of both PACE and WPP providers stated that the interdisciplinary care teams meet to exchange information, ensure that individuals' needs are being met, and address changes in the health status of individuals.

The four hospital-based palliative care programs we identified use interdisciplinary care teams to coordinate services. These programs' teams include medical directors, social workers, chaplains, nurses, psychologists, and case managers. Two of the hospice-based palliative care programs developed partnerships with local hospitals and use interdisciplinary care teams to assist individuals. Two other hospice-based palliative care programs use interdisciplinary care teams of health care professionals to coordinate medical, nursing, social work, and spiritual services. Staff from one of these programs told us that because case

managers facilitate communication among different medical providers and ensure that tests performed have a clear purpose, unnecessary or duplicate tests are avoided. One hospice-based palliative care program's interdisciplinary care team consists of a nurse, social worker, and palliative care physician who coordinate care and monitor the quality of care provided. The two palliative care programs operated by health care systems use interdisciplinary care teams composed of nurses, social workers, chaplains, and pharmacists. The care team of one of these palliative care programs makes treatment recommendations and enhances coordination among medical staff. The other of these palliative care programs provides social and psychological support and assists individuals with transitioning between the hospital and their homes. One hospice-based palliative care program uses a single case manager to assist individuals with coordinating services.

In the ALTCS program, each Medicaid beneficiary is assigned a case manager. The case manager aids the beneficiary in obtaining necessary services, coordinates service delivery, and consults with other providers as needed. ALTCS case managers refer beneficiaries to other social service agencies when additional services are needed. ALTCS officials noted that a unique feature of the program is that it provides institutional, supportive, and all other medical and long-term care services under one agency and under the supervision of a single case manager for each beneficiary. An official also noted that the ALTCS program fosters continuity of care and care coordination at the end of life through the case manager and the integrated delivery of services from a single agency.

Programs Use Supportive Services

The programs we identified provide a variety of supportive services to assist individuals near the end of life. The PACE providers we interviewed are required to deliver supportive services such as personal care services, adult day care, social work services, and meal delivery. Representatives of one PACE provider stated that one strength of PACE is the integration of all Medicare- and Medicaid-covered services, which includes the supportive services, such as personal care services, covered by Medicaid. Representatives of a PACE provider reported that when individuals become too frail to come to the day center, a designated team visits individuals in their homes to provide personal care, nursing, and physician services. Representatives of this provider also described how they assist individuals residing in residential care facilities and adult foster homes who are nearing the end of life by providing additional staff support and visits from the primary care physician.

The supportive services offered by WPP providers include social services, personal care services, adult day care, environmental adaptations,[16] meal delivery, and transportation to medical appointments. Representatives of a WPP provider stated that they also involve local community resources such as religious institutions and friends to ensure that individuals receive the assistance they need in their homes and communities. Representatives of another WPP provider stated that the most common supportive services they provide are home care, transportation, and day center activities. Representatives of this provider noted that as individuals get closer to the end of life, additional home care support can be provided.

Supportive services provided by the ALTCS program include home health services, homemaker services, personal care, transportation, adult day care, and home delivered meals. ALTCS officials stated that the type of supportive services provided can vary significantly depending on a beneficiary's level of functioning and the level of support provided by the family. A CMS official noted that two-thirds of ALTCS beneficiaries receive supportive services in their homes or communities, which the official cited as being above the national average.

The palliative care programs we identified either provide supportive services directly to individuals nearing the end of life or assist individuals with obtaining such services. One hospice-based palliative care program provides individuals telephone calls and visits and assists individuals with applying for other benefits. Another hospice-based palliative care program provides supportive care that includes nursing and social work services and spiritual counseling. A palliative care program that is operated by a health care system provides individuals with 24-hour nursing support and pastoral services. A palliative care program operated by a hospital helps individuals establish supportive services, such as personal care services, at the time of discharge from the hospital.

Programs Provide Pain and Symptom Management

All the programs we identified provide pain and symptom management or assist with the coordination of such services. Representatives of the WPP and PACE providers we interviewed incorporate pain and symptom

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[16]An environmental adaptation is equipment or physical adaptations to an individual's home that enable the individual to have greater independence and functional access and ensure the health and safety of the individual. For example, installing equipment in a bathroom to make it more accessible for an individual with mobility impairments is an environmental adaptation.

management into the care they provide. For example, representatives of a provider of both PACE and WPP described how individuals they serve are able to receive pain and symptom management services whenever they feel such services are necessary. One PACE provider we interviewed offers pain and symptom management to individuals nearing the end of life, and a palliative care team visits individuals in the home when they are unable to attend the PACE day center. Other providers of PACE and WPP obtain assistance from local hospices to help provide pain and symptom management services, such as overnight nursing, spiritual care, or pain management. ALTCS provides pain and symptom management to individuals when such services are needed. Representatives of the 12 palliative care providers we interviewed provide or assist with coordinating pain and symptom management for individuals in either the home or hospital setting.

Programs Offer Family and Caregiver Support

Programs we identified offer family and caregiver support through a variety of services. PACE and WPP providers offer family and caregiver support through personal care services, which can help alleviate demands on a caregiver, and respite services provided in the home. In addition, the adult day centers operated by the PACE providers we visited offer respite opportunities for the caregivers of the individuals who attend the day care programs. One WPP provider also operates a day center to provide caregivers with respite. The ALTCS program provides support for caregivers through personal care, respite, and adult day care services.

Most of the palliative care programs we identified also provide support to family members and caregivers. They provide this support in a variety of ways. Two hospice-based palliative care programs use social workers to assist families and caregivers with end-of-life decision making and accessing community agencies and resources. Another hospice-based palliative care program uses an interdisciplinary care team to assist families in making end-of-life decisions. One hospital-based palliative care program, two hospice-based palliative care programs, and one palliative care program operated by a health care system provide bereavement support to family members. One health care system's palliative care program provides 24-hour nursing support for individuals in their homes, which assists caregivers, and another palliative care program operated by a hospice assists family members with coordinating in-home support services. Two hospital-based palliative care programs assist families with coordinating care upon an individual's discharge from the hospital. Officials from one hospice-based palliative care program and a palliative

care program operated by a hospital both stated that they provide education about end-of-life care to family members.

Programs Foster Communication among the Individuals, Families, and Program Staff

The programs we identified communicate frequently with individuals and their families regarding end-of-life issues. Representatives of the PACE, WPP, and palliative care providers and ALTCS officials we interviewed stated that they work with individuals and their families to develop a plan of care that reflects each individual's choices. For example, a representative of a PACE provider described how the interdisciplinary care team fosters communication with the individual about what type of care he or she wants to receive at the end of life, including pain and symptom management. Representatives of a provider of both PACE and WPP described how the interdisciplinary care team establishes goals with the individual and includes a physician and social worker to facilitate discussions involving end-of-life issues. A hospital-based palliative care program's interdisciplinary care team holds meetings with family members to discuss an individual's health status, prognosis, and end-of-life wishes, and another palliative care program has discharge coordinators follow up with individuals for as long as services are required. An ALTCS official stated that case managers discuss with beneficiaries what their needs are and what care they want to receive. Representatives of palliative care, PACE, and WPP providers informed us that they develop close, trusting relationships with individuals through their frequent communication to facilitate discussions about end-of-life care.

Representatives of PACE, WPP, and palliative care providers we interviewed stated that communicating with individuals and their families about end-of-life issues earlier, rather than later, in the individual's illness makes it easier for both the individual and family to manage the decisions they face when the individual is closer to death. Representatives of a WPP provider stated that they have continuous conversations with individuals and families about plans for the end of life, and representatives of a PACE provider noted that they have these discussions early because such discussions become more challenging when someone is very near the end of life. Representatives of another WPP provider stated that they have monthly conversations with individuals about which life-saving measures they would like implemented as their condition worsens. A PACE provider's staff visits an individual nearing the end of life every other day to ensure that the individual's and family's needs are being met. Representatives of a palliative care provider described how they repeatedly discuss with individuals near the end of life the availability of other services such as hospice.

Programs we identified use a variety of tools to foster communication among the members of the care team concerning individuals' needs as they near the end of life. Staff members of a provider of both PACE and WPP use a checklist to identify changes in an individual's condition. The checklist is completed at an individual's periodic review or whenever there is a change in health status and helps inform the care team about the need to discuss end-of-life planning with the individual. Representatives of providers described the benefits of electronic medical records in promoting communication among members of the care team. Representatives of a PACE provider and a palliative care program stated that creating an electronic medical record accessible to all members of the care team facilitates communication among the team regarding the condition of each beneficiary and increases the quality of care. A palliative care provider distributed laptop computers and handheld wireless devices to all clinical staff. Using these devices, clinical staff can both access and input information when they visit an individual's home, which keeps all staff who interact with the individual informed. Another palliative care provider shares clinicians' notes and correspondence electronically, which enhances communication.

Representatives of a hospice-based palliative care provider in Oregon stated that the physicians they work with are more comfortable discussing end-of-life issues with their patients since the 1997 enactment in Oregon of the Death with Dignity Act, which focused attention in the state on end-of-life care and the options available to individuals. Representatives of a palliative care program operated by a health care system we interviewed stated that passage of this act helped create an environment in Oregon where end-of-life issues are discussed more openly.

Programs Initiate and Encourage Advance Care Planning

The WPP, PACE, and palliative care providers initiate or encourage advance care planning to assist individuals with planning for the end of life, making decisions about future medical care, and sharing information with family members. Representatives of all the PACE providers stated that they assist individuals with advance care planning tasks, such as completing advance directives and identifying health care proxies, that is, those who can make health care decisions on behalf of the individuals. Representatives of a provider of PACE and WPP stated that each individual begins the advance care planning process as soon as he or she is admitted to the program. This provider's staff members work with individuals to identify health care proxies and persuade individuals to communicate their decisions to family members. Representatives of a WPP provider stated that the staff have monthly conversations with

individuals about their end-of-life choices, such as do-not-resuscitate orders. Representatives of another WPP provider stated that the care team encourages individuals and their families to plan for the end of life, and representatives of a provider of both PACE and WPP discuss with individuals all the medical services and interventions they wish to receive.

Officials of palliative care programs stated that they offer assistance to individuals enrolled in their programs in completing advance directives and informing their families of any decisions they have made about their end-of-life care. One palliative care program operated by a hospice assists individuals with completing advance directives and informing family members of their decisions for the end of life. Palliative care programs operated by hospitals assist individuals with advance care planning tasks such as completing advance directives and making medical decisions.

Representatives of a PACE provider in Oregon stated that they use Physician Orders for Life-Sustaining Treatment (POLST) forms to assist all individuals in their program with advance care planning.[17] The POLST form is a physician's order that communicates which medical interventions should be performed in the event of a health emergency. Similar to other advance directives, the POLST form allows individuals to document their choices regarding the use of life-sustaining procedures; a representative in Oregon stated that, unlike other advance directives, POLST forms are physician orders, which are more effective at communicating an individual's preferences to providers, particularly when the individual is transferred across health care settings. A representative of an Oregon PACE provider stated that the POLST form makes an individual's wishes clear and, because it is in the form of a physician's order, legally protects medical personnel, including emergency medical technicians, when they carry out an individual's documented choices during an emergency.

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[17]The POLST form was developed by a multidisciplinary task force of health care professionals and representatives from governmental organizations and health care institutions in Oregon.

Providers Find Challenges to Delivering Certain Key Components of End-of-Life Care

Representatives of providers we interviewed described challenges they encounter to delivering some of the key components of end-of-life care. They described difficulties delivering supportive services and family and caregiver support to rural residents because of travel distances, fewer community-based service options, and an inability to hire adequate numbers of staff in rural areas. Representatives of providers also stated that they believe physician training and practices can inhibit the provision of pain and symptom management and advance care planning to individuals nearing the end of life.

Providers Encounter Challenges Delivering Supportive Services and Family and Caregiver Support to Rural Residents

Representatives of providers we interviewed described difficulties delivering supportive services and family and caregiver support to rural residents because of travel distances, lack of community-based services, and insufficient numbers of nursing and personal care staff in rural areas. Representatives of providers we interviewed stated that significant distances between residents in rural areas make it difficult to provide family and caregiver support, such as respite care, and supportive services, such as personal care services. The length of time it takes for personal care staff to travel between individuals in rural areas decreases the number of services the providers can deliver in a day. In addition, representatives of providers told us that increases in fuel costs have affected how many services they can provide. Representatives of providers we interviewed also described how unpaved roads and inclement weather can increase travel time or prevent travel entirely when serving rural residents. Representatives of one provider stated that the challenge of providing transportation in rural areas is one of the barriers that has prevented the provider's expansion into rural areas of the state.

Representatives of providers we interviewed also cited the limited availability of certain services in rural areas as a challenge to serving individuals nearing the end of life who reside in those areas. Representatives of providers described difficulties in delivering supplies and medications to rural residents. For example, representatives of a hospice-based palliative care provider noted that the pharmacy service it contracts with to provide home delivery of medications cannot provide daily delivery in very rural areas and inclement weather may further delay deliveries. To address the problem, this provider has contracted with local rural pharmacies to provide emergency medication; however, in a two-county area, only one pharmacy is open 24 hours a day, making it difficult for individuals to access medications in an emergency. Representatives of another hospice-based palliative care provider and a WPP provider stated that they are sometimes unable to coordinate supportive services, such as

meal delivery and personal care services, for individuals in rural areas because they are unable to locate providers of these services in these regions. In addition, representatives of providers noted that a lack of transit services makes it difficult to provide individuals living in rural areas with transportation to medical appointments or day centers.

Representatives of providers stated that an insufficient number of nursing staff and personal care workers in rural areas makes it difficult to provide end-of-life care to those residents. For example, representatives of a provider of both PACE and WPP noted that it is often difficult to hire staff to work in more remote geographic areas, and they cited this as a barrier to expanding the provider's services into additional rural areas of the state. In addition, representatives of one hospice-based palliative care provider that serves a remote rural area stated that they have been unable to maintain adequate numbers of health care workers to provide services to its patients because such workers are increasingly choosing to relocate to urban areas. Representatives of another hospice-based palliative care provider in a rural region also stated that they have difficulty finding qualified staff to fill these positions.

State officials we interviewed said that PACE is not a feasible option in rural areas because of the requirement that the providers operate an adult day center. Representatives of a provider that was formerly a PACE provider stated that it was difficult to remain financially solvent as a PACE provider in a rural community because there were not enough eligible individuals to support an adult day center model. This provider ended its participation in PACE because the community it served did not have enough eligible individuals to justify the expense of a day center. Also, in rural areas, the distance to the PACE adult day center from the residences of individuals enrolled in the program can be a challenge for the PACE program's transportation services.

Providers Encounter Physician Training and Practices as Challenges to Providing Pain and Symptom Management and Advance Care Planning

Representatives of providers we interviewed described how they believe physician training and practices may present challenges to providing pain and symptom management and advance care planning to individuals nearing the end of life. Representatives of providers stated that physicians often do not receive adequate training in pain and symptom management. A physician we interviewed who is the director of a hospital-based palliative care program stated that he believes because physicians lack

training to recognize the need for pain and symptom management, individuals nearing the end of life often have difficulty accessing such services.[18] Representatives of other palliative care providers we interviewed agreed that lack of physician training in pain and symptom management is a challenge to the provision of pain and symptom management. Representatives of a hospital-based palliative care provider believe that many medical schools do not provide sufficient training for physicians in pain and symptom management. Representatives of a palliative care provider operated by a health care system stated that they believe most physicians are not trained to provide pain and symptom management to individuals nearing the end of life. A recent article in the *New England Journal of Medicine* (NEJM) has also noted that physicians receive little or no training in the use of medications for pain and symptom management.[19]

Representatives of providers we interviewed also cited physician practices as challenges to individuals receiving pain and symptom management services as they near the end of life. A representative of a hospital-based palliative care provider stated that some physicians are reluctant to refer individuals to the program so that they can receive pain and symptom management because these physicians do not understand or recognize the need for such care. Representatives of providers we interviewed also described how, in their experience, physicians may fail to address pain in a timely manner. A representative of a hospital-based palliative care provider stated that patients' severe pain may go untreated while physicians, intent on finding the cause of the pain, order extensive diagnostic testing. Representatives of a palliative care program operated by a health care system stated that some physicians perform aggressive medical procedures on individuals nearing the end of life. These representatives stated that they believe some physicians view providing pain and symptom management as "giving up" on a patient.

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[18]In September 2006, the American Board of Medical Specialties (ABMS) approved the development of Hospice and Palliative Medicine as a subspecialty. As a result of this approval, the first ABMS-recognized examinations for this subspecialty will likely be administered in 2008.

[19]G. Gazelle, "Understanding Hospice – An Underutilized Option for Life's Final Chapter," *The New England Journal of Medicine*, vol. 357, no. 4 (2007), 321-324.

Representatives of providers we interviewed described how physicians often do not engage in advance care planning with individuals nearing the end of life. For example, representatives of a hospice-based palliative care provider stated that they believe physicians do not spend enough time talking with individuals about end-of-life care options such as hospice. As was recently reported in NEJM, physicians receive little training in the compassionate discussion of end-of-life issues.[20] Furthermore, ALTCS officials stated that, in their experience, physicians often do not inform individuals about advance directives. Representatives of a hospice-based palliative care provider stated that physicians sometimes provide individuals with incorrect information about care options for the end of life. Representatives of a PACE provider told us that some physicians resist ending curative care to allow individuals nearing the end of life to receive only supportive care services, and the article published in NEJM reported that some physicians regard the death of patient as a professional failure.[21]

Agency Comments and Our Evaluation

In commenting on a draft of this report, CMS stated that the report is a useful description of a diverse set of provider types in very different settings, each of which provides useful services to persons coming to the end of life. CMS noted that the report is especially helpful as a time approaches when more Americans will be living with serious and eventually fatal chronic conditions. CMS also stated that it was useful that our report included individuals living with serious chronic conditions who might live for some years. However, CMS suggested that we avoid using the term terminal illness when referring to such individuals. We note that, in our draft report, we used this term only in the context of discussing the Medicare hospice benefit, which is, by definition, a benefit for individuals with terminal conditions. CMS also stated that we should mention other important components of end-of-life care including, for example, having the appropriate medical diagnosis and having all possible opportunities for a meaningful life. However, these issues are beyond the scope of our report. CMS also provided technical comments, which we incorporated where appropriate. CMS's comments are reprinted in appendix I.

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[20]Gazelle, "Understanding Hospice – An Underutilized Option for Life's Final Chapter."

[21]Gazelle, "Understanding Hospice – An Underutilized Option for Life's Final Chapter."

As agreed with your office, unless you publicly announce the contents of this report earlier, we plan no further distribution of it until 30 days from its date. At that time, we will send copies of this report to the Administrator of CMS and to other interested parties. We will also make copies available to others upon request. In addition, this report will be available at no charge on the GAO Web site at http://www.gao.gov.

If you or your staff have any questions about this report, please contact me at (202) 512-7114 or kingk@gao.gov. Contact points for our Offices of Congressional Relations and Public Affairs may be found on the last page of this report. GAO staff who made major contributions to this report are listed in appendix II.

Sincerely yours,

Kathleen King
Director, Health Care

DEPARTMENT OF HEALTH & HUMAN SERVICES   Centers for Medicare & Medicaid Services

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OCT 1 2 2007

Office of the Administrator
Washington, DC 20201

TO: Kathleen King
              Director, Health Care
              Government Accountability Office

FROM: Kerry Weems
              Acting Administrator
              Centers for Medicare & Medicaid Services

SUBJECT: Government Accountability Office's (GAO) Draft Report:
              "End-of-Life Care: Key Components Provided by Programs in Four
              States" (GAO-08-66)

Thank you for the opportunity to review and comment on the above referenced subject draft report. We appreciate the GAO's interest in end-of-life care. The Centers for Medicare & Medicaid Services (CMS) is, as always, concerned about the quality of care provided.

This report is useful in describing a diverse set of provider types in quite different settings, each of which is providing very useful service to persons coming to the end of life. It is quite helpful to have such a wide-ranging inquiry and description, especially as we approach a time when so many more Americans will be living with serious and eventually fatal conditions. CMS noted a few items that might readily be addressed in order to make the report even more clear.

We find it very useful that the report includes persons living with serious chronic conditions who might live for some years. The Program of All-Inclusive Care for the Elderly (PACE) and other programs do not require a reliable expectation of dying soon that is inherent in the prognostic requirement for hospice. It would be good to make this point explicitly, and to avoid using the term "terminal illness" in order to avoid the sense that "dying" is a clearly definable phase of life. Usually explicit terms like "living with eventually fatal illness" or "coming to the end of life" are more informative to the reader. If the report explicitly used the trajectories model (e.g., from the IOM report, or from the June Milbank Quarterly article by Lynn et al), the uncertainty over the timing of death might make more sense to the reader. This could just be footnoted.

We would note with approval that the current CMS work to provide patient assessments across provider types (the Continuity Assessment Record and Evaluation instrument and demonstration) would sustain and spread the good work that is mentioned on the middle

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of page 20, in which PACE and palliative care are finding that shared electronic records
help quality of care.

There are a few items of "context" that are so important in the care of all patients that
they are probably not mentioned in site visits. Nevertheless, even for persons coming to
the end of life, such conventionally important elements as these continue to be important:
(1) having the appropriate medical diagnosis and treatment interventions; (2) counting on
reliable services 24/7, across settings and time; and (3) having all possible opportunities
for meaningful life (including personal relationships, spiritual experience, and productive
work). Most likely, the programs visited, and the visitors, assumed that these were part
of the package. However, they are well worth noticing, since otherwise it seems that care
near the end of life might not have to prioritize these elements. This could be added in a
short sentence or even a footnote, just to be clear that they still matter.

This is a very useful project and well-reported and will be of help in our work to ensure
quality and value in care for persons living with fatal illness. Thank you for the
opportunity to review the draft. We appreciate the insights gained from the site visits and
so helpfully documented.

Appendix II: GAO Contact and Staff Acknowledgments

GAO Contact

Kathleen King, (202) 512-7114 or kingk@gao.gov

Acknowledgments

In addition to the contact named above, key contributors to this report were Nancy A. Edwards, Assistant Director; Beth Cameron Feldpush; Krister Friday; John Larsen; and Andrea E. Richardson.