END-OF-LIFE CARE

Key Components Provided by Programs in Four States

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.