ADVANCE DIRECTIVES

Information on Federal Oversight, Provider Implementation, and Prevalence

Why GAO Did This Study

Advance directives, such as living wills or health care powers of attorney, specify—consistent with applicable state law—how individuals want medical decisions to be made for them should they become unable to communicate their wishes. Many individuals receive medical care from Medicare and Medicaid funded providers during the last 6 months of life, and may benefit from having advance directives that specify treatment preferences. According to IOM, advance directives are most effective when part of a comprehensive approach to end-of-life care called advanced care planning.

GAO was asked to review information related to advance directives. This report examines (1) how CMS oversees providers’ implementation of the PSDA requirement; (2) what is known about the approaches providers use and challenges they face to inform individuals about advance directives; and (3) what is known about the prevalence of advance directives and how it varies across provider types and individuals’ demographic characteristics. To do this work, GAO reviewed CMS documents and survey data reported by state survey agencies. In addition, GAO reviewed CMS documents and survey data reported by state survey agencies into CMS’s Certification and Survey Provider Enhanced Reporting system about covered providers’ implementation of the PSDA requirement. GAO also conducted a literature review of peer reviewed articles and federal government reports. In addition, GAO interviewed CMS officials and stakeholders representing providers and individuals likely to benefit from advance directives.

What GAO Found

The Centers for Medicare & Medicaid Services (CMS) oversees providers’ implementation of the advance directive requirement in the Patient Self Determination Act (PSDA) to maintain written policies and procedures to inform individuals about advance directives, and document information about individuals’ advance directives in the medical record by providing guidance and monitoring covered providers. Covered providers include hospitals, nursing homes, home health agencies (HHAs), hospices, and Medicare Advantage (MA) plans that receive Medicare and Medicaid payments. CMS, an agency within the Department of Health and Human Services (HHS), provides operations manuals, memoranda, and model documents to these providers to inform them about the advance directive requirement and describe how the agency will monitor providers’ implementation. Because individual states are responsible for administering contracts with and providing guidance to Medicaid managed care plans, also specified in the PSDA, CMS ensures that the contracts include the advance directive requirement, but does not issue guidance to these plans. To monitor providers’ implementation of the advance directive requirement, CMS primarily relies on other entities. CMS enters into agreements with state survey agencies to periodically survey and report data, which CMS collects, on deficiencies related to advance directives for hospitals, nursing homes, HHAs, and hospices. CMS also relies on accrediting organizations to survey providers that participate in the Medicare program through accreditation and subsequently make recommendations to CMS regarding providers’ participation in Medicare. In addition, CMS reported reviewing MA and Medicaid managed care plans’ contracts to determine that they include the advance directive requirement.

Approaches used to inform individuals about advance directives vary by type of provider, but providers face similar challenges, according to stakeholders interviewed and literature GAO reviewed. For example, hospitals, nursing homes, HHAs, and hospices inform individuals about advance directives during the admission process, while MA plans and Medicaid managed care plans inform individuals during enrollment. Challenges in informing individuals about advance directives include discomfort talking about end-of-life issues and lack of staff time for such discussions. Providers may address these challenges by using leading practices, such as patient education or population specific materials.

Many adults have advance directives, but estimated prevalence varies by provider type and an individual’s demographic characteristics. In 2013, 47 percent of adults over the age of 65 had an advance directive, according to the Institute of Medicine (IOM) report, Dying in America. However, the prevalence of individuals with advance directives varies by type of provider and demographic characteristic. For example, a National Center for Health Statistics report found that 88 percent of discharged hospice patients had advance directives in 2007 compared to 65 percent of nursing home patients in 2004. Studies GAO reviewed found that individuals who were older, white, had higher education or incomes, or were women were more likely to have advance directives than others.

HHS provided technical comments on a draft of this report, which were incorporated as appropriate.