Evidence Roadmap:



End-of-Life Care and Medicare's Hospice Benefit

In 2013, AcademyHealth's Translation and Dissemination Institute launched its Listening Project, which aims to identify the most pressing health services research needs of leaders in health policy and health care delivery for the coming three to five years. The 2014 Listening Project Report identified several research and data gaps related to Medicare. In response to what we heard from the Medicare policy community, AcademyHealth has created this series of evidence roadmaps to identify existing resources related to these gaps. These roadmaps represent a selected minimal set of key resources rather than comprehensive list of relevant research. The roadmaps are intended to help policy analysts and other research users better understand whether a perceived research gap represents an actual lack of evidence or a failure of existing evidence to reach the policy arena, that is, a failure of adequate translation and dissemination. AcademyHealth undertook this roadmap with the support of the Robert Wood Johnson Foundation.

While acknowledging the potential controversies and concerns associated with end-of-life care, Listening Project respondents discussed a need for research to inform policy decisions about such care, including the Medicare hospice benefit. Although Medicare pays for care for eight in ten decedents annually, it is not the only payer for services received at the end-of-life. In 2011 Medicaid was the primary payer for 63 percent of all nursing facility stays, including in nursing homes, where about a quarter of all Medicare beneficiaries die. Medicare also does not cover other types of care commonly received by individuals near the end-of-life, including many long-term services and supports. Although end-of-life care is financed through a patchwork of sources, this roadmap focuses on research related to Medicare's role in providing and paying for services during the last part of beneficiaries' lives, including through the Medicare hospice benefit.

Systematic Reviews

Can Palliative Care Reduce Futile Treatment? A Systematic Review

Harris I, Murray S., BMJ Support Palliative Care. 2013 Dec; 3(4):389-98.

This review concluded that while existing evidence suggests palliative care reduces costs, there is less evidence about whether quality-of-life improves. This research has been hampered by disparate outcome measures, small sample sizes, and a lack of randomized designs.

Retrospective Studies of End-Of-Life Resource Utilization and Costs in Cancer Care Using Health Administrative: A Systematic Review

Langton J, Blanch B, Drew A, Haas M, Ingham J, Pearson S. Palliative Medicine. 2014;28(10):1167-1196.

This review synthesized retrospective observational studies on resource utilization and/or costs at the end of cancer patients' lives.

Disparity in Hospice Utilization by African American Patients With Cancer

Ramey J, Chin S. Am J Hosp Palliat Care. 2012 Aug;29(5):346-54.

This literature review concluded that African Americans with cancer have lower levels of hospice utilization than other cancer patients and that disparities exist after entry into hospice. Age, gender, geographic location, preference for aggressive care, and knowledge of hospice influenced hospice use by these patients.

Individual Studies

Hospices' Enrollment Policies May Contribute to Underuse of Hospice Care in the United States Aldridge Carlson M, Barry S, Cherlin E, McCorkle R, Bradley E. Health Aff (Millwood). 2012 Dec; 31(12):2690-2098.

Researchers used results from a national survey of hospice enrollment policies to examine the barriers to hospice access for terminally ill patients and broader impacts on overall hospice utilization. The authors discussed implications for Medicare's hospice *per diem* rate for patients with complex needs.

Advance Care Planning and Quality of End-of-Life Care in Older Adults

Bischoff K, Sudore R, Miao Y, Boscardin W, Smith A. J Am Geriatr Soc. 2013 Feb; 61(2): 209-214.

This study used data from the Health and Retirement Study to determine the influence of advance care planning on quality of end-of-life care. Researchers found that advanced care planning was associated with less in-hospital death and increased hospice use.

Racial Differences in Location Before Hospice Enrollment and Association with Hospice Length of Stay Johnson K, Kuchibhatla M, Tulsky J. J Am Geriatr Soc. 2011 Apr; 59(4): 731-737.

This study connected race and location to hospice length of stay with implications for the development of interventions to increase timely access to hospice.

Hospice Enrollment Saves Money for Medicare and Improves Care Quality Across a Number of Different Lengths-of-Stay.

Kelley A, Deb P, Du Q, Aldridge Carlson M, Morrison R. Health Aff (Millwood). 2013 Mar; 32(3):552-561.

Researchers used data from the Health and Retirement Study, 2002-08, and individual Medicare claims to analyze cost savings for beneficiaries enrolled in hospice as compared to a non-hospice control group. Researchers found that hospice patients had significantly lower rates of hospital service use and in-hospital death than matched controls.

Association Between The Medicare Hospice Benefit and Health Care Utilization and Costs for Patients With Poor-Prognosis Cancer

Obermeyer Z, Makar M, Abujaber S, Dominici F, Block S, Cutler D. JAMA. 2014;312(18):1888.

This study concluded that Medicare fee-for-service patients with poor-prognosis cancer receiving hospice care had significantly lower rates of hospitalization, intensive care unit admission, and invasive procedures at the end of life, along with significantly lower total costs than did similar patients not receiving hospice services.

Half of Older Americans Seen in Emergency Department in Last Month of Life; Most Admitted to Hospital, And Many Die There

Smith A, McCarthy E, Weber E, Cenzer I, Boscardin J, Fisher J, Covinsky K. Health Aff (Millwood). 2012 June; 31(6): 1277-1285.

Authors examined emergency department use in the last month of life and compared hospice enrollees to non-hospice enrollees. Researchers found that hospice enrollees visited emergency departments (EDs) less often than those not enrolled in hospice with implications for Medicare spending since ED visits contribute to end-of-life costs.

What Length of Hospice Use Maximizes Reduction in Medical Expenditures Near Death in the U.S. Medicare Program?

Taylor D, Ostermann J, Van Houtven C, Tulsky J, Steinhauser K. Soc Sci Med. 2007 Oct; 65(7): 1466-78.

This retrospective case/control study of Medicare decedents compared hospice decedents with propensity scored matched control decedents based on their likelihood of dying while in hospice. Researchers found that hospice use reduced Medicare expenditures in the last year of life after hospice initiation, but that expenditure reductions varied by primary condition.

The Effect of Hospice on Medicare and Informal Care Costs: The U.S. Experience

Taylor D. J Pain Symptom Manage. 2009 Jul; 38(1): 110-114.

The author examined costs incurred by patients and families when Medicare beneficiaries enroll in hospice versus non-hospice care. The author concluded that formal out-of-pocket costs do not differ by hospice use, but families experience higher informal costs when a patient chooses hospice.

Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009

Teno J, Gozalo P, Bynum J, Leland N, Miller S, Morden N et al. JAMA. 2013;309(5):470.

This study analyzed Medicare claims data to identify changes in end-of-life care for Medicare beneficiaries. Researchers found that although more people are dying at home, more people are also experiencing stays in an intensive care unit in their last month of life.

Is a Home Care Network Necessary to Access the Medicare Hospice Benefit?

Van Houtven C, Taylor D, Steinhauser K, Tulsky J. J Palliat Med. 2009 Aug; 12(8): 687-694.

Authors examined how informal care relationships influence hospice use and concluded that while beneficiaries under formal home care had a higher likelihood of enrolling in hospice, the presence of informal care did not influence the likelihood of hospice enrollment but was associated with longer use among those who did enroll.

Grey Literature

Medicare Hospice Payment Reform: A Review of the Literature (2013 Update)

Abt Associates.

This review provided background on the current hospice payment system and presents relevant research informing hospice payment reform. It is organized around four issues: (1) describing growth and change in the hospice industry; (2) aligning reimbursement with resource use; (3) identifying payment system vulnerabilities; and (4) responding to proposals for payment reform.

Medicare Hospice Payment Reform: Analyses to Support Payment Reform Abt Associates.

The analyses measured how the hospice benefit is being utilized in itself and in conjunction with other Medicare services and implications for the provision of more patient-centered care for beneficiaries at the end of life.

Tracking Improvement in the Care of Chronically-III Patients: A Dartmouth Atlas Brief on Medicare Beneficiaries Near the End of Life

Goodman D, Fisher E, Wennberg J, Skinner J, Taber S, Bronner K. The Dartmouth Atlas of Health Care. Hanover (NH): The Dartmouth Institute for Health Policy and Clinical Practice; 2013.

This Dartmouth Atlas brief analyzed the costs and quality of end-of-life care for Medicare beneficiaries over time and across geographic regions, noting an overall improvement in end-of-life care for Medicare over time but with geographic variation in that improvement.

Report to the Congress: Medicare and the Health Care Delivery System Chapter 5: Medicare Hospice Policy Issues

Medicare Payment Advisory Commission (US). Washington, D.C. Medicare Payment Advisory Commission; 2013.

The Medicare Payment Advisory Commission (MedPAC) recommended that Congress reform Medicare hospice payment systems, improve hospice accountability, and examine payment for hospice in nursing facilities. MedPAC analyzed Medicare claims data from 2008-2012 to reach these recommendations. MEDPAC reports historically contain rich material on hospice.

Ongoing Research

Default Options in Advance Directives

Scott Halpern, University of Pennsylvania

This multicenter, randomized clinical trial is examining whether default options in advance directives among patients with incurable diseases can improve patients' quality of life and reduce resource utilization without reducing the number of days that patients are alive and living outside of an acute-care hospital.

Increasing Access to Hospice Care for Older African Americans: A National Study Kimberly Johnson, Duke University & NIH/NIA.

This research will identify the practices of hospice providers (i.e. community partnerships) which are associated with greater use of hospice care by older African Americans in their service area to help inform options to reduce racial disparities in hospice use.

Search Strategy

Using the National Library of Medicine MeSH browser, AcademyHealth staff first identified key words and associated MeSH (medical subject headings) terms. Staff used the key words to search various databases and journals for relevant articles and then examined the bibliographies of these articles to identify additional studies. Staff searched health care, health policy, trade group, government, and academic websites for grey literature and chose studies most relevant to Medicare services provided at the end-of-life, including hospice care. Because the purpose of these roadmaps was to inform current policy, searches focused on years 2010 through 2014 with older studies included when appropriate. Two AcademyHealth members, chosen for their relevant expertise, reviewed the draft Roadmaps, and AcademyHealth staff then updated the document to incorporate the reviewers' comments and suggestions.

Databases/Journals: EBSCO Host—Academic Search Elite, Business Source Elite; SAGE Publications; Medical Care Research & Review; Health Affairs; Google Scholar; HSRProj; PubMed/MEDLINE

Websites: AARP Public Policy Institute; U.S. Centers for Medicare and Medicaid Services; Robert Wood Johnson Foundation; Kaiser Family Foundation; Medicare Payment Advisory Commission; SCAN Foundation (RWJF); Dartmouth Atlas of Health Care; RWJF Changes in Health Care Financing & Organization program; Alliance for Health Reform; National Health Policy Forum.

Key words: end of life care; end of life AND Medicare; hospice; Medicare AND hospice; terminal care; terminal care AND Medicare; palliative care; palliative care AND Medicare

Inclusion criteria: Studies/resources related to quality and cost of end-of-life care under Medicare and studies/resources related to utilization, quality, and cost of the Medicare hospice benefit

Key to Cited Resources

- **Systematic reviews** provide insights from a body of research literature.
- Individual studies provide findings from key pieces of research.
- Grey literature provides relevant evidence published by organizations whose primary activity is not publishing.
- Ongoing research includes studies currently underway that addresses key questions.