First Medicare Demonstration of Concurrent Provision of Curative and Hospice Services for End-of-Life Care

Hospice developed in the United States in the 1970s as a way to address unmet needs for endof-life care: support for pain and symptom management provided in the location and manner that the patient and family prefer. In Europe and Australia, hospice is available from the time of diagnosis of an advanced lifelimiting illness onward, but in the United States, the Medicare hospice benefit restricts eligibility for these services to patients who no longer receive curative treatment.

We provide background and analysis of the first Medicare hospice demonstration in 35 years that will test the concurrent provision of curative and hospice services for terminally ill individuals with a life expectancy of six months or less.

This demonstration is a harbinger of potential policy changes to hospice and palliative care in the United States that could reduce barriers to end-of-life care that aligns with patient and family preferences as the demand for care increases with an aging population. (*Am J Public Health*. Published online ahead of print June 16, 2016: e1–e4. doi:10.2105/AJPH.2016. 303238)

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ore than 1.6 million Americans received hospice care in 2014, a set of comprehensive medical, psychosocial, and spiritual palliative care services consistent with public health strategies to prevent or mitigate pain and suffering among individuals with advanced life-limiting illness and their loved ones. The benefits of palliative care include better symptom control, fewer and less intensive hospital admissions in the last month of life, less anxiety and depression for the patient, and less distress for the caregiver.² More than 85% of hospice patients receive care through the Medicare Hospice Benefit (MHB), which requires that beneficiaries have a terminal illness and a prognosis of less than six months to "revoke" traditional curative care and elect hospice care for symptom management and maximize quality of life at end of life.³ The MHB restriction creates a barrier to effective care for individuals with advanced illness who would prefer to simultaneously pursue curative treatment while accessing expert symptom management through hospice services. These patients must postpone enrollment in hospice; as a result, they have a short length of stay and do not receive the full potential benefit of hospice.

This article contextualizes potential policy changes resulting from a new Medicare hospice

demonstration beginning in 2016 and from the anticipated increased demand for palliative care services driven by the aging workforce. We begin by describing the development of the MHB, drawing partially from personal experience of one author (S. R. C.). We then describe the informal provision of concurrent curative and hospice care (henceforth "concurrent care") through open-access hospice and a variety of small studies. Finally, we offer cautions and recommendations on the design of the first Centers for Medicare & Medicaid Services (CMS) demonstration of hospice care since 1980: the Medicare Care Choices Model (MCCM) program.

DEVELOPMENT OF THE MEDICARE HOSPICE BENEFIT

Dame Cicely Saunders developed hospice in England in the 1960s as a mixture of curative and palliative therapies. ⁴ Other than the United States, countries that provide government payment for palliative care services

continue to do so concurrently with curative treatment, including those in Europe⁵ and Australia. How did the situation develop in which patients had to give up curative treatment to access the comprehensive services of a hospice program in the United States?

As hospices proliferated in the United States in the 1970s, Congressional leaders called for an independent study of the process and its potential for cost containment.4 Although hospice initially developed to serve cancer patients-who have defined and predictable disease courses some Congressional leaders believed that hospice was a possible answer to the problem of longterm care for the elderly.4 Twenty-six organizations were selected from around the United States to participate in the 1980 national hospice demonstration project; during the demonstration, patients were free to continue curative oncology treatments.7

Meetings were held with Congressional staff to discuss the development of the law based on the results of the demonstration

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and regulatory conditions of participation. Hospices were eager for a government benefit to help grow the hospice movement in the United States and advocated that it reimburse all-inclusive care for the terminally ill.8 During these negotiations, the budget director for the Reagan Administration insisted that Medicare should not pay for simultaneous curative and hospice services because costs would be too high.⁹ The hospice leadership participating in the meetings eventually agreed to the restriction, and Congress created the new Medicare benefit in $1982.^{3}$

OPEN-ACCESS HOSPICE: INFORMAL CONCURRENT CARE

Patients and clinicians alike struggled with the transition from curative to palliative care required by the MHB.⁴ When the MHB was implemented in 1983, hospice average length of stay was 70 days, but by 2000, it had decreased to 48 days, partially attributed to the effect of federal regulation.⁴ As a result, hospice organizations began looking for ways to provide concurrent care preferred by many patients and clinicians and aligned with the original hospice philosophy.

The MHB payment structure allows variability in how hospices interpret what "comfort care" is available to patients, as detailed in the Conditions of Participation. As a capitated payment system, the MHB provides hospices with a per-member, perday payment to provide all services and therapies; in 2015, hospices received approximately \$160 per diem to provide routine home care. A patient who needs less expensive treatment must

balance a patient who needs more expensive or intense treatment. Some services are deemed too expensive to provide even if they are palliative, such as when treatments cost more than the \$4800 a month available from the MHB. In the 1990s, some large hospices began leveraging the flexibility of the capitated payment system to offer open-access hospice. ¹¹

In a hospice choosing to provide concurrent care, patients may be able to receive more expensive treatments such as palliative chemotherapy, radiation therapy, and intravenous medications. 11 By 2009, 29% of hospices reported having an open-access enrollment policy, but two thirds of those reported restrictions on enrollment such as excluding chemotherapy or radiation. 12 Larger hospices serving more than 100 patients per day or nonprofit hospices were more likely to report having open enrollment policies, likely because they are more able to distribute the financial risk of high-cost patients.12 Openaccess hospices offer these services through careful stewardship of MHB per-diem reimbursements, earlier hospice admission and increased revenue from length of service, and substantial fundraising efforts. Insurance companies also have developed concurrent care programs for their own beneficiaries, such as Aetna's Compassionate Care Program.¹³

EVIDENCE BASE FOR CONCURRENT CARE

The development of the MHB did not end efforts to test providing concurrent care from diagnosis through end of life.

One notable example was

a national program funded by the Robert Wood Johnson Foundation and directed by Ira Byock.14 Twenty-two demonstration programs were conducted in multiple clinical settings and patient populations to test new care models.14 Although limitations in the program design meant that outcomes were not comparable across projects and sites, the program did provide evidence that existing care settings could feasibly integrate palliative care. Moreover, the program showed that projects providing concurrent curative and palliative care could be sustained, replicated, and expanded.

Smaller studies of concurrent curative and palliative or hospice services also provided evidence as to potential positive outcomes. Randomized trials of early access to palliative care for patients with cancer, such as the landmark Temel study, found longer median survival despite receiving less aggressive care, improved symptom control, and improved quality of life.15 Cost savings in the provision of hospice and palliative care are attributed to reductions in the use of medical services, reductions in overall hospital costs, reductions in laboratory and intensive care unit costs, and significant decreases in hospital admissions, nursing home admissions, emergency department visits, and use of outpatient consultation services. 15-17

MEDICARE CARE CHOICES MODEL DEMONSTRATION

The Affordable Care Act made several steps toward reducing the strict tradeoff between curative and hospice services. ¹⁸

First, Section 2302 established reimbursement of concurrent care for children covered by public insurance, which sets precedence for policy changes to adult hospice care under the MHB and provides additional data on potential barriers and facilitators to implementation. Second, Section 3120 authorized a demonstration project to test the effect of concurrent care on patient care, quality of life, and cost-effectiveness of care for adults.

CMS solicited applications for sites to participate in the MCCM demonstration in March 2014.¹⁹ The Request for Applications described key elements of the MCCM demonstration. Eligible Medicare beneficiaries would be those eligible for hospice but who had not yet used the MHB; they also would need to live at home and have diagnoses of advanced cancers, chronic obstructive pulmonary disease, congestive heart failure, or HIV/AIDS. For participating individuals, hospices would be responsible for providing access to comprehensive hospice services in accordance with the Conditions of Participation. In return, hospices would receive up to \$400 per month for beneficiaries enrolled for more than 15 days or \$200 per month for those enrolled for less than 15 days.

In May 2015, CMS invited 141 hospices to participate in a five-year demonstration, half of which would be randomly assigned to begin the demonstration in January 2016 and half in 2018. The program as announced has several laudable features. First, it is an innovative, nationwide test of providing concurrent care for hospice patients, the first Medicare hospice demonstration in 35 years. Second, a third-party independent evaluator will assess the effect

of the demonstration on access to hospice, health care use, clinical outcomes, and quality of care. Third, the demonstration tests more than simply cancer diagnoses but restricts access to participants with diagnoses that either typically include shorter lengths of stay in hospice or are easier to prognosticate; this is an appropriately narrowed scope given the restriction to the existing MHB prognostic requirement. Finally, the demonstration uses a creative design that may allow evaluators to identify barriers, facilitators, and best practices in the first cohort of participants and to test design modifications in the second cohort

However, the MCCM design has several limitations. First, this is a narrow study to examine whether concurrent care reduces barriers to enrolling in home hospice for those patients with a six-month life expectancy, such as those patients who are ready for hospice but who prefer treatments that are more expensive than most hospices can afford. Given eligibility criteria, we estimate that fewer than 15% of hospice patients will be eligible for MCCM, suggesting that hospices may have significant problems enrolling participants and that the results of the study may not be generalizable to the full population of people who currently use hospice. The administrators of the MCCM demonstration may want to consider expanding eligibility to improve recruitment and generalizability.

Second, MCCM creates conflicting financial and ethical pressures for participating hospice organizations. For both MHB and MCCM patients, the hospice must provide a comprehensive interdisciplinary assessment within the first three days of care

to establish a plan of care. If a patient receives care for only three days, the hospice will receive about \$480 for the MHB patient or \$200 for the MCCM patient. After completing the comprehensive assessment for the MCCM patient, the hospice staff then must debate whether, given the patient's acuity and medication needs, the patient will be best served by the full hospice service and how to talk to the patient about transitioning to MHB. To provide the first 15 days of care, the hospice will receive about \$2400 for the MHB hospice patient or \$400 for the MCCM demonstration participant. The math becomes more complex when considering a patient whose expensive medication can be billed directly to Medicare when the participant is enrolled in MCCM but not when the patient enrolls in MHB. MCCM partially aims to provide preference-aligned care for patients who are resistant to entering hospice because of their fear that hospice means giving up hope associated with curative treatment. If these patients enroll in MCCM, they may not be willing to transition to MHB, even if they cease seeking curative treatment and the MHB is the more appropriate reimbursement mechanism for the services sought.

Third, MCCM requires hospices to report quality measures to external evaluators, some already used by the organization as proposed in the application and some required by the evaluators to facilitate cross-site comparisons. Evaluators should closely monitor data collection and reporting from organizations participating in the demonstration, because in many hospices the culture of systematic data collection and rigorous measurement remains in its infancy.

CMS began mandating quality assessment and improvement in Medicare-certified hospices in 2008.¹⁰ In 2010, only 66% of hospices reported regularly using a standardized assessment tool for pain and symptom management, and 40% or less of the data were collected "mostly electronically."20 Although hospices are now required to report data for seven National Quality Forumendorsed quality measures, 21 little is known about the sophistication of hospice organization's data collection and quality metric use. The MCCM evaluation provides a unique opportunity to closely examine and enhance quality improvement infrastructure in participating hospices.

IMPLICATIONS FOR THE FUTURE

MCCM is one of several efforts to address problems caused by the structure of the MHB. For example, in 2016, the payment structure will be modified to match the service-intense periods in a hospice patient's enrollment and encourage more intensive care around the time of death, while also discouraging long-stay patients.²² Hospices will receive the regular routine home care per diem for the first 60 days of care. but the rate will decrease on day 61. In addition, a service intensity add-on may be paid on the last seven days of life for professional visits of up to four hours. These changes will need to be monitored closely to ensure the aggregate effect is to reduce barriers in access to care and improve the provision of end-of-life care in accordance with diverse patient preferences.

Policy changes also should address demand for coordinated

interdisciplinary care for patients with advanced illness before their last six months of life, because patients experience uncontrolled symptoms up to two years before death. As a recent Institute of Medicine report noted, the need for prehospice palliative care will increase dramatically as Medicare-eligible baby boomers are diagnosed with advanced illness. 23 As a result of the regulatory restrictions of the MHB, US prehospice palliative care has developed and rapidly expanded over the past decade²⁴ to allow patients to receive simultaneous curative and palliative care in the hospital; this model of care is slowly expanding to be available in the home as well. However, existing reimbursement mechanisms for prehospice palliative care do not facilitate the provision of interdisciplinary care, for example, if only a physician or nurse practitioner can bill for a visit under a fee-for-service model. New policy and payment mechanisms are needed to better manage this growing population. We recommend that CMS conduct a future demonstration to address broader questions than those addressed by MCCM, such as testing the cost and effect of concurrent palliative care from point of diagnosis onward for care models that better suit the needs of difficult-to-prognosticate diseases such as Alzheimer's disease and heart failure.

In five years, policymakers will be able to use the results of MCCM to inform regulatory or legislative changes to MHB. Stakeholders will focus on the potential savings of the model of concurrent care tested in MCCM, hoping that the demonstration will replicate findings from other studies of care models. However, policymakers should be wary of replicating the tradeoff

made in developing the MHB, in which cost concerns were prioritized over the model of care valued by patients and clinicians for allowing a smoother transition from aggressive curative treatments to end-of-life care focused on symptom relief and enhanced quality of life. In the meantime, approximately 5800 hospice locations will continue to deliver care under the MHB,1 and a small number will continue to provide concurrent care in other ways, such as open-access hospice. Finding ways to increase the use of hospice and palliative care-such as through concurrent care—will be a significant step toward addressing the public health problem of the burden of advanced life-limiting illness. AJPH

CONTRIBUTORS

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REFERENCES

- 1. National Hospice and Palliative Care Organization (NHPCO). NHPCO's Facts and Figures: Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization; September 2015. Available at: http://www.nhpco.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf. Accessed January 18, 2015.
- 2. Hughes MT, Smith TJ. The growth of palliative care in the United States. *Annu Rev Public Health*. 2014;35:459–475.
- 3. Medicare program; hospice care—HCFA. Final rule. *Fed Regist.* 1983; 48(243):56008–56036.
- 4. Buck J. Policy and the re-formation of hospice: lessons from the past for the future of palliative care. *J Hosp Palliat Nurs*. 2011;13(6):S35–S43.
- 5. Centeno C, Lynch TJ, Donea O, Rocafort J, Clark D. EAPC Atlas of Palliative Care in Europe 2013. Full ed. Milan, Italy: EAPC Press; 2013. Available at: http://www.eapcdevelopmenttaskforce.eu/images/booksdocuments/ AtlasEuropafulledition.pdf. Accessed December 29. 2015.

- 6. Wright M, Wood J, Lynch T, Clark D. Mapping levels of palliative care development: a global view. *J Pain Symptom Manage*. 2008;35(5):469–485.
- 7. Mor V, Greer DS, Kastenbaum R, eds. *The Hospice Experiment*. Baltimore, MD: Johns Hopkins University Press; 1988.
- 8. Connor SR. Development of hospice and palliative care in the United States. *Omega (Westport)*. 2007–2008;56(1): 89–99.
- 9. Freudenheim M. Administration sets payment rates for hospices under Medicare. *New York Times*. December 11, 1983. Available at: http://www.nytimes.com/1983/12/11/us/administration-sets-payment-rates-for-hospices-undermedicare.html. Accessed April 6, 2016.
- 10. Centers for Medicare & Medicaid Services (CMS), HHS. Medicare and Medicaid programs: hospice conditions of participation. Final rule. *Fed Regist.* 2008; 73(109):32087–32220.
- 11. Wright AA, Katz IT. Letting go of the rope–aggressive treatment, hospice care, and open access. *N Engl J Med.* 2007; 357(4):324–327.
- 12. Aldridge Carlson MD, Barry CL, Cherlin EJ, McCorkle R, Bradley EH. Hospices' enrollment policies may contribute to underuse of hospice care in the United States. *Health Aff (Millwood)*. 2012; 31(12):2690–2698.
- 13. Krakauer B, Agostini J, Krakauer R. Aetna's compassionate care program and end-of-life decisions. *J Clin Ethics*. 2014; 25(2):131–134.
- 14. Byock I, Twohig JS, Merriman M, Collins K. Promoting excellence in end-of-life care: a report on innovative models of palliative care. *J Palliat Med.* 2006;9(1): 137–151.
- 15. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med.* 2010;363(8):733–742.
- 16. Taylor DH Jr, Ostermann J, Van Houtven CH, Tulsky JA, Steinhauser K. What length of hospice use maximizes reduction in medical expenditures near death in the US Medicare program? Soc Sci Med. 2007;65(7):1466–1478.
- 17. Kelley AS, Deb P, Du Q, Aldridge Carlson MD, Morrison RS. Hospice enrollment saves money for Medicare and improves care quality across a number of different lengths-of-stay. *Health Aff (Millwood)*. 2013;32(3):552–561.
- 18. Patient Protection and Affordable Care Act, 42 USC §18001(2010). Available at: https://www.cms.gov/
 Regulations-and-Guidance/HIPAA-Administrative-Simplification/
 Affordable-Care-Act/index.html.
 Accessed January 8, 2013.
- 19. Request for Applications: Medicare Care Choices Model. Baltimore, MD: Centers for Medicare & Medicaid Innovation; 2014.

- Available at: http://innovation.cms.gov/Files/x/MCCM-RFA.pdf. Accessed August 27, 2015.
- 20. Hanson LC, Schenck AP, Rokoske FS, et al. Hospices' preparation and practices for quality measurement. *J Pain Symptom Manage*. 2010;39(1):1–8.
- 21. Centers for Medicare & Medicaid Services, Hospital Quality Reporting Program. HIS Manual: Guidance Manual for Completion of the Hospice Item Set (HIS). Baltimore, MD: Centers for Medicare & Medicaid Services; 2014. Available at: https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Hospice-Quality-Reporting/Downloads/HIS-Manual. pdf. Accessed August 17, 2015.
- 22. Centers for Medicare & Medicaid Services (CMS), HHS. Medicare Program; FY 2016 Hospice Wage Index and payment rate update and hospice quality reporting requirements. Final rule. *Fed Regist*. 2015;80(151):47141–47207.
- 23. Institute of Medicine (IOM). Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington, DC: National Academies Press; 2014. Available at: http://resources.iom.edu/widgets/endoflife/quiz.html#. VN4Lq-bF-So. Accessed February 13, 2015.
- 24. Dumanovsky T, Augustin R, Rogers M, Lettang K, Meier DE, Morrison RS. The growth of palliative care in U.S. hospitals: a status report. *J Palliat Med*. 2016;19(1):8–15.