There are downsides to everything; there are unintended consequences to everything.

Steve Jobs

Now in its fifth decade, the Medicare hospice benefit program has transformed the dying experience in the US. However, with an aging population dying of multiple chronic conditions, newer medical treatments to prolong life, and concerns that length of stay in hospice may be too short, it is time to update the Medicare hospice benefit so it can continue to achieve the goal of providing person and family-centered care for seriously ill and dying individuals. The most advocated change is for “concurrent care” in which a person may receive treatment that may be curative or life extending while continuing to access palliative care services. In making this change or others, careful consideration must be given to potential unintended consequences so that the important gains of the hospice benefit are not lost.

Why Change the Medicare Hospice Benefit?

The payment model and initial regulations for the Medicare hospice benefit were formulated in part based on the National Hospice Study led by Brown University in the 1980s. At that time, the payment model was based on the typical disease trajectory of cancer treatments. Eligibility for benefits was based on an expected prognosis of 6 months and persons must agree to opt out of curative or life-extending treatments for illnesses that would otherwise be terminal within this period. The disease trajectory of advanced cancer during the 1980s was often characterized by sharp functional decline during the last months of life. This pattern does not fit noncancer causes of death today. And with improvements in cancer treatment, this trajectory also no longer fits some types of advanced cancer. As a result, the current eligibility criteria that require a person to opt out of curative treatment contributes to a shorter length of stay in hospice, as evidenced by the Medical Care Choices Model that allowed concurrent care and realized an increase use of hospice services. In addition, the current payment model can limit access to palliative treatments that improve the quality of life (eg, blood transfusion, drainage of pleural effusions), but do not extend life. When the Medicare hospice benefit was created, Medicare Advantage was in its infancy and hospice was treated as a “carve out,” with persons leaving a Medicare Advantage plan to return to traditional Medicare when hospice was required.

A Potential Serious Unintended Consequence

Alternative payment models (APMs) at this time, which are currently being tested or are under development by the Center for Medicare and Medicaid Innovation (CMMI) to expand access to palliative services and hospice without forgoing treatment that may be curative or life extending, use a predominant common design (prospective, capitated payment with rewards, penalties, or both based on the quality of care and use). With the Medicare hospice benefit, changing one capitated payment system to another payment model with capitation should raise concerns of profiteering (eg, not making needed visits to dying persons and their family) of the Medicare hospice benefit that may affect the quality of care. Simplistically, changing the traditional Medicare payment...
model that rewards volume (though with concerns of overtreatment) to a capitated payment model may result in not providing needed care in the pursuit of higher profit margins. The most serious concern of harm is inappropriate referral of patients with reversible medical conditions to hospice that may contribute to their premature or avoidable death as with the Liverpool Care Pathway in the UK.2

**Recommendations for Testing of New APMs**

The CMMI performs an important role and difficult task in creating, testing, and implementing an APM that incentivizes appropriate referrals to hospice, that is economically feasible, and contains safeguards to ensure that referrals are based on a person's informed preferences and their medical condition. Three key considerations should be addressed in this process.

First, health care is a complex system requiring a multifaceted approach that balances oversight without hindering innovation. The testing of a new APM must examine not only the proposed changes (eg, payment and eligibility), but use best practices of oversight through quality measures, the monitoring of complaints, and the use of state or federal surveys to assess compliance with the conditions of participation. At the early stage of model development, transparency with external expert review is needed to ensure potential unintended consequences are considered and a mixed-method approach for evaluation should be used to identify unanticipated, unintended consequences. Recommendations for how quality measures and oversight will counter concerns over anticipated consequences should be published in the notice of the proposed APM in the Federal Register.

Second, testing of APMs should include new approaches to survey visits (state, federal, or both) that are undertaken to examine whether the new payment model is in compliance with federal standards. As outlined in an Institute of Medicine report, compliance inspections should use existing quality data to focus patient and family interviews on key processes and outcomes that are concerning. Consideration should be given to testing a 2-tier survey process in which poorly performing hospice programs receive an extended survey visit, more frequent surveys, or both.

Third, careful consideration should be given to whether new quality measures need to be developed and tested as part of the evaluation of or prior to the actual implementation of a new APM. Electronic medical records can provide an efficient means to measure the quality of care. However, decisions at the end of life can involve trade-offs between the quality and the quantity of life. The electronic medical record, a legal document, reflects the health care clinician's perceptions that may be in error or are different from the perceptions of the patient, family, or both regarding communication, decision-making, and symptom palliation. It is important, despite additional survey costs, to include patient-centered measures in evaluating quality of care, especially regarding concerns about communication and medical decisions at the close of life.

Fourth, some have recommended using randomized clinical trials to test proposed APMs due to concerns of selection bias and regression to the mean. A concern with the rigid randomized clinical trial approach are problems with implementation of the intervention, such as hospice programs dropping out, low patient enrollment, or both as noted in the Medicare Care Choices Model. Another approach to consider for testing proposed APMs is dynamic evaluation, which allows changes to the interventions to address concerns in the design of the payment model after a reasonable period of testing.

One final caveat to the redesign of the Medicare hospice benefit is that the assumption may be wrong that education, shared decision-making, and advance care planning will result in most individuals opting for hospice or palliative care consultation earlier in their disease trajectory. Despite the growth of the Medicare hospice benefit, the median length of stay in hospice has not improved. Enrollment in hospice remains essentially flat, with nearly 40% of hospice decedents from 2011 to 2018 only enrolling after an acute care hospitalization.3 Many individuals may never embrace the philosophy of the Medicare hospice benefit, and the costs savings may not offset additional
payments for hospice or an APM. Although it is time to update the Medicare hospice benefit, caution is needed to anticipate and avoid potential unintended consequences. Dying is a pivotal time in medical care when there is no chance to right a wrong decision.

ARTICLE INFORMATION


Open Access: This is an open access article distributed under the terms of the CC-BY License. © 2023 Teno JM. JAMA Health Forum.

Corresponding Author: Joan M. Teno, MD, MS, Department of Health Services, Policy, and Practice, School of Public Health, Brown University, 63 Chachapacasset Rd, Providence, RI 02806 (jnten076@gmail.com)

Author Affiliations: Health Services, Policy, and Practice, School of Public Health, Brown University, Providence, Rhode Island; Behavioral and Policy Sciences Department, Rand Corporation, Arlington, Virginia.

Conflict of Interest Disclosures: Dr Teno reported receiving funding from the Centers for Medicare and Medicaid Innovation as an investigator on the evaluation of the value-based insurance design and receiving funding from the Centers for Medicare & Medicaid Services on the national implementation of the CAHPS Hospice Survey. This JAMA Forum post is independent of that work. Dr Teno also reported receiving a salary as an adjunct staff member at Rand Corporation.

REFERENCES


