Seriously Ill Individuals—A Canary in the Coal Mine for Medicare’s Transition to Accountable Health Care?

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Don’t save the canary. Fix the coal mine.
Seth Godin

As fundamental changes to payment models for health care are underway, it is important to ensure that vulnerable populations such as the seriously ill and dying are protected. One of the strategic objectives of the Centers for Medicare & Medicaid Services (CMS) Innovation Center, which was authorized under the Affordable Care Act and tasked with designing, implementing, and testing new payment models, is to increase the number of Medicare beneficiaries in a “care relationship with accountability for quality and total cost of care.” Medicare Advantage (MA) is on track to cover care for 69% of Medicare beneficiaries by 2030. In 2018, 48% of Medicare decedents already were in MA or an Accountable Care Organization (ACO), and 7.9% (161,158) of Medicare decedents aged 66 years or older were in an MA or ACO program during the year prior to death but lost attribution (ACO) or disenrolled from their MA plan.¹

Costs are easy to measure. In 2011, 18.2 million seriously ill individuals—defined as the top 5% of health care costs—accounted for 57% of health care spending in the US.² Among seriously ill persons with high medical costs, about 11% are dying, 49% experience discrete medical events (ie, a 1 and done occurrence), and 40% are chronically ill with persistently high costs. Altogether, these 3 populations accounted for health care spending of $17,500 per person in 2011.

In contrast to costs, measuring quality of care for serious illness is more complicated.³ Because patients with high needs and high costs have more complex interactions with health care systems, persons who are seriously ill are the virtual “canaries in the coal mine” for quality of care—the stress test of MA plans or ACOs to deliver competent, coordinated, person- and family-centered care. In particular, there are 2 important concerns about current quality-of-care measures used for accountability.

First, quality-of-care measures publicly reported on the CMS Care Compare websites focus on payment silos, such as for acute care hospitalization, home health, nursing home care, or hospice. Measures such as hospital mortality and 30-day rehospitalizations, as well as perceptions of the quality of outpatient care in MA plans, hospital care, home health services, or hospice care provide important information about these payment silos, which are mostly organized by setting of care rather than patient populations or episodes of care. But Medicare beneficiaries experience care as a whole, not just by payment silos. For example, a seriously ill person might experience transitions from home to hospital to skilled nursing home—and then finally return to home with home health services.

Second, pathways of care for seriously ill patients typically result in either a cure, new stability of chronic illnesses with continued high costs, or death. Given the variability of these pathways, it is important to ensure that treatment decisions reflect informed and evolving goals of care. In addition, seriously ill persons have varying preferences—for example, care preferences of healthy middle-aged persons with an acute myocardial infarction may differ markedly from those of an 80-year-old patient with multiple chronic conditions that have resulted in functional impairment. Utilization measures such as hospitalizations during the last 30 days of life do not capture the vital role of shared decision-making or the development of care plans that help persons achieve their goals of care, if

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possible. A seriously ill person’s perceptions of communication about the goals of care and care coordination is increasingly important as economic incentives align with providing cost-effective care and containing health care costs.

Despite these concerns, there are encouraging developments. The family of Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys, including the MA CAHPS survey, have laid the groundwork for composite quality measures that are important to the care of seriously ill patients, such as obtaining needed care, care coordination, and physician communication. New measures have been validated for assessing care of such patients in outpatient palliative care and home-based serious illness programs. However, efforts are still needed to validate such measures beyond persons enrolled in palliative care programs and to further develop domains of quality of care (eg, spirituality) that may increase in importance during the final disease trajectory for those who die.

The timing of surveys is important. The advantage of a retrospective survey of bereaved family members regarding quality of care is that the denominator is clear. A process of care either occurred or it did not. Assessing either the seriously ill person’s or the family members’ perceptions of quality of care prospectively must be sensitive to the complexity of decision-making in the seriously ill. A quality measure for accountability that forces a conversation that a person is not psychologically ready to have or that results in psychological distress is not helpful or desirable.

The vision of the CMS Innovation Center is for all Medicare beneficiaries to receive care from an MA plan or an ACO program that is held accountable for both total costs and quality. For those organizations, seriously ill patients are likely to account for more than half of total health care costs. If MA plans or ACOs are rewarded for lowering the cost of these patients with high needs and high costs, they must be held accountable for their quality of care by appropriately weighting the experiences of these seriously ill patients. Recent research by Meyers et al4 attests to the important quality-of-care concerns of persons with a dementia diagnosis cared for by MA plans in obtaining needed care and customer service.

In the CMS Innovation Center vision of “care relationships with accountability,” care for seriously ill individuals contributes heavily to the costs, but transparency is currently lacking regarding the quality component for these individuals when evaluating the value of care. If the goal is accountability for both costs and quality, the CMS must ensure both components of the value equation are considered for seriously ill patients.

Ensuring that vulnerable populations such as the seriously ill and dying are protected will require the development and rigorous testing of accountability measures as part of demonstration programs evaluating new models of care. Ultimately, seriously ill persons are the canaries in the coal mine that demand close attention as new Medicare payment models are implemented to ensure person- and family-centered care.
REFERENCES


