Hospice "Carve in" to Medicare Advantage:
Importance of Transparency and Accountability

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January 10, 2015

Hospice has been a carve out of Medicare Advantage (MA) plans with concerns of lack of care coordination and financial incentives for the MA plans results in an early hospice referral to avoid the high costs at the end of life. Potentially, carving hospice back in MA will result in higher rate of Medicare Beneficiaries receiving appropriate access to palliative care services by removing the requirement that patient must opt out of active treatment for their terminal illness. If the MA plan refers the patient to hospice or palliative care services, the Medicare Beneficiary could receive concurrent care consisting of palliative care and active treatment of their terminal illness.

"Carving in" hospice benefits will allow patients to receive hospice or palliative care concurrently with curative care. However, this carve-in will create financial incentives for MA plans to refer to hospice later or to provide less skilled palliative care services.

Currently, a higher proportion of Medicare beneficiary decedents with MA coverage die on hospice services compared to traditional fee for service Medicare (i.e., in 2011, 49.1% vs. 45.0%). Carving hospice back into MA plan coverage may allow concurrent care. However, it is important to guard against the possibility that because of concerns about costs of providing both hospice and curative care, MA plans might stint on the quality or quantity of care for such patients, or offer a more limited set of services than patients are entitled to within the Medicare Hospice Benefit (as already occurs, for example, with the Program for All-Inclusive Care of the Elderly program). The dying are a vulnerable population that is often cognitively impaired, experience a high rate of unmet needs, suffer from burdensome symptoms while dying, and are high utilizers of health care. The proposed policy will change the financial incentives for this vulnerable population that already has important unmet needs and concerns with the quality of care at the close of life.

With changes in financial incentives, valid measures of care quality are of utmost importance for ensuring transparency and accountability. If quality of care is not front and center, the momentum to improve end-of-life care in the United States could face a serious setback.[1]

Recommendation: That legislation that carves hospice back into MA should include funding and provision for CMS to implement a population-based, post-death survey that measures the degree to which Medicare Beneficiaries enrolled in an MA plan receive high quality care at the end of life.

Patient and family experiences of care are the most important indicator of quality of care at the end of life.

The dimensions of quality of end-of-life care differ fundamentally from those in most other areas of medicine, in which mortality rates, functional status, and processes of care are crucial. For example, quality medical care for a previously healthy 72 year old with an acute myocardial infarction can be measured by whether treatment protocols known to improve survival and/or function have been followed, such as the use of aspirin to minimize infarct size.[2] The vast majority of patients in these circumstances would want efforts to focus on improving survival and/or restoring function. In contrast, what defines "quality" for the 72 year old dying of stage IV non-small cell lung cancer may be completely different. Those dying from chronic, progressive, and eventually fatal illnesses have widely-variant goals and preferences for their care, and these goals and preferences cannot be assumed reliably by their health care providers. Decisions regarding medical treatment in these circumstances depend on each individual's preferences about both the quality and quantity of life, requiring health care providers to go beyond knowledge of the disease trajectory, and the impact of various treatment approaches on survival and function, and to approach each patient as an individual with specific needs, preferences, and expectations. Communication and individualized shared decision-making are crucial to both defining and achieving quality of care for each patient. In other words, patient-centeredness of care – the degree to which care is "… respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions" is a particularly vital element of quality of care at the end of life. Indeed, quality of care at the end of life can only be understood in terms of what matters most to each patient; therefore, reliable and valid measures of quality must include assessments of the patient's own subjective experience. The patient's experience is the key "outcome."

Since dying patients may not be able to describe their own experiences, surveys of their family members are needed. There are important challenges to measuring the care of the dying – the vast majority of dying persons are cognitively impaired or too sick to be interviewed in the last days of life. Symptoms escalate in the last days of life, and more than one-half of dying people experience health care transitions in which decisions are made regarding the use of life sustaining treatment. For the dying, family members play an important role in decision making and providing personal care. As noted by the World Health Organization, the unit of care for palliative care is the dying patient and his or her family or close friends.[3] Surveys of bereaved family members are an efficient and valid means of studying decision making and quality of end of life care, avoiding the difficult and costly problem of prospectively identifying terminally ill patients.[4] In addition, this approach minimizes the bias of missing interviews among the sickest patients who are unable to be interviewed in the last weeks of life,[5] and creates a method for comparing results across different settings of care and payment models.

Experience of care surveys can be used to identify concerns about quality of care, and inform quality improvement.

We are poised to implement the needed systems to ensure that what matters for each dying person and his or her family is measured, reported, and used to drive quality. Nearly two decades of research and use of bereaved family member surveys has resulted in actionable measures that were adopted for implementation among hospices nationwide through the CAHPS Hospice Survey as of January 2015. Work toward this milestone began in 1997, when Teno and colleagues recognized the need to improve quality measures to guide quality improvement with a long-term goal of implementing national accountability measures of end of life care.[6-8]

Surveys of family members have shown that:

- The highest quality hospice care experiences for dying patients occur in homes rather than nursing homes and hospitals; [9]
- Blacks receive worse hospice care than whites;[10]
- There is wide regional variation in the intensity of care at the end of life[11]
- Higher intensity care and more transitions in care in the last few days of life are associated with family members reporting concerns about communication and decision-making;[11],[13]
- Families' reports of their experiences of hospice care have gotten worse over time, suggesting that overall quality of care has gotten worse, not better from 2000 year to 2010/2011; [12]

With important policy changes such as the "carve in" of hospice into MA, we must ensure that what matters to dying persons and their family not only counts but is actually "counted," and that actionable measures ensure transparency and accountability. The use of consumers to report on what "matters" through the use of post-death survey is an important viable quality measure that will ensure that care is consistent with patient informed preferences and goals of care.

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