

The Emerging Picture of Quality of Care in Hospice

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Do current hospice quality measures provide meaningful information to help consumers and policymakers distinguish between high- and low-quality providers?

- Existing quality measures are not providing consumers with an indication of the overall quality of hospice care around admission. CMS and RTI are developing a composite measure addressing whether patients receive all elements of a comprehensive assessment around admission.
- Currently, no appropriate quality measures exist to assess hospice care in the last days of life. CMS and RTI are developing quality measures that will assess whether patients receive visits by hospice staff at the end of life.
- Concern persists about patients who are discharged alive from hospice, indicating a potential need for a new quality measure focusing on these patients.

The Medicare hospice benefit, which was permanently established in 1986, provides patients and families with palliative and supportive services to help address physical, psychosocial, and other symptoms at the end of life. The ultimate goal of hospice care is to help the patient and family receive care aligned with their preferences, while improving quality of life as death nears. By 2014, nearly half of all Medicare beneficiaries who died used hospice care,¹ reflecting expanded access to these services and consumers' desire for this holistic care near the end of life. However, the aggressive growth in hospice services, investigative journalism, and anecdotal stories has generated concern that quality of hospice care is widely variable and sometimes suboptimal. In response, stakeholders and the public have increasingly called for measures of the quality of health care delivery at the end of life. Defining and measuring the quality of hospice care is challenging, given its strong ties to patient preferences,

the terminal health status of patients, and the challenges of an interdisciplinary team delivering services in various settings, including patients' homes and residential care settings. National data gathering and public reporting are in their initial stages; consequently, consumers currently have limited information about the quality of hospice care to help them select a provider.

Given the historical lack of information in this area, RTI is conducting research that will provide a first look at hospice quality of care. This research is asking three key questions:

- How is the quality of hospice care currently measured?
- When public reporting begins, will current quality measures provide consumers with meaningful information to help them distinguish between high-quality and low-quality providers?
- What new measures are needed to assess hospice quality and support patient and family decision-making?

How is the quality of hospice care currently measured?

Efforts to reach consensus on defining hospice quality—including The National Consensus Project for Quality Palliative Care—generated the measures currently implemented in the Centers for Medicare & Medicaid Services (CMS) Hospice Quality Reporting Program. The Hospice Item Set, a patient-level instrument developed by RTI, is used to gather data on the seven quality measures currently included in this program. Additionally, the Consumer Assessment of Healthcare Providers and Systems (CAHPS) Hospice Survey was recently implemented. Information gathered from this post-death survey will provide a retrospective understanding of patients’ and families’ experience with hospice care, as reported by family caregivers.

Measures Related to Quality of Care at Hospice Admission

The Hospice Quality Reporting Program currently implements seven quality measures developed by RTI and endorsed by the National Quality Forum^a (Table 1). These seven measures focus on processes of care around the time of hospice admission, and capture management of pain, shortness of breath, and bowel function, as well as discussions of patient preferences regarding life-sustaining treatments and spiritual concerns.

Measures Related to Hospice Discharge: Quality of Care Near Death

As patients approach the end of life, hospices often provide increasingly intense and frequent care for physical and psychosocial symptoms. They also support family caregivers as they prepare for the death of the patient.

Table 1. Seven Quality Measures Included in the Hospice Quality Reporting Program

Measure Title ^a	Measure Definition	Purpose/Rationale for Measure
Bowel Regimen (NQF #1617)	Patients who are given a bowel regimen to address constipation within 1 day of beginning or continuing an opioid, or who have documentation as to why this was not needed	Most patients prescribed opioids to manage pain or other symptoms develop some degree of constipation after opioid initiation or dose increases. Reducing opioid-induced constipation can reduce patient discomfort and improve quality of life.
Pain Screening (NQF #1634)	Patients who are screened for the presence or absence of pain (and if present, rating of its severity) using a standardized quantitative tool during the admission evaluation for hospice/initial encounter for palliative care	Pain screening improves the provider’s awareness of the presence of pain and is the essential first step for quality pain management and treatment.
Pain Assessment (NQF #1637)	Patients who received a comprehensive pain assessment to determine the severity, etiology and impact of their pain within 1 day of screening positive for pain	A comprehensive pain assessment will improve the provider’s awareness of pain severity, cause of the pain, and effect of pain on quality of life, a critical basis for quality pain management and treatment.
Dyspnea Screening (NQF #1639)	Patients who are screened for the presence or absence of dyspnea (shortness of breath) and its severity	Screening for shortness of breath, a distressing symptom for many patients and their families, is necessary to determine its presence and severity and to develop treatment plans.
Dyspnea Treatment (NQF #1638)	Patients who received dyspnea treatment within 1 day of screening positive for dyspnea (shortness of breath)	Effective treatment for shortness of breath, a distressing symptom for many patients and their families, should be made available to alleviate symptom distress for patients with dyspnea.
Treatment Preferences (NQF #1641)	Patients whose medical record includes documentation of life-sustaining preferences	Patients who are given the opportunity to express their preferences regarding life-sustaining treatment are more likely to receive care consistent with their values, improving patient and family outcomes, including greater satisfaction with care.
Beliefs and Values (Modified NQF #1647)	Patients with clinical record documentation of spiritual/religious concerns or documentation that the patient/family did not want to discuss	Discussion and documentation of spiritual care needs can ensure that the full hospice team provides care for the physical, psychosocial, and spiritual needs of the patient and caregiver(s).

^a The National Quality Forum consensus-based endorsement is the gold standard for quality measure endorsement (more information regarding the process is available at http://www.qualityforum.org/how_we_do_it.aspx). The short measure titles and parenthetical measure numbers listed in Table 1 are the official National Quality Forum labels for these measures. Find more information for each of these measures on the National Quality Forum website (www.qualityform.org).

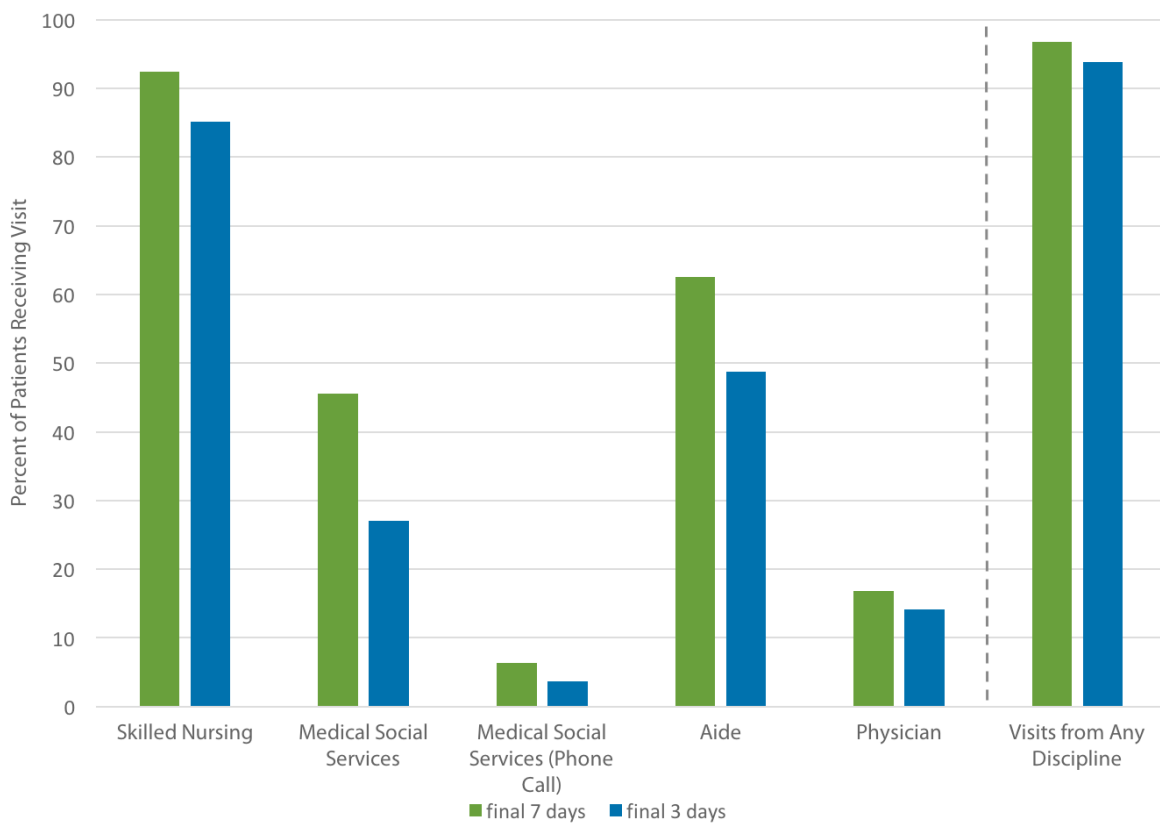
The last week of life is typically the period in the terminal illness trajectory with the highest symptom burden for patients and caregivers. Particularly during the last few days before death, patients and their families experience myriad physical and emotional symptoms, necessitating close care and attention from a well-coordinated and integrated hospice team.

While the CMS Hospice Quality Reporting Program does not currently include measures of the quality of hospice care near death, prior studies have shown that hospice patients' caregivers prioritize hospice responsiveness as a very important aspect of high-quality care.² In a focus group with six hospice patients' caregivers conducted by RTI, participants indicated that visits from nurses, social workers, and other members of the interdisciplinary care team are valuable in addressing a variety of care

needs during the final days before death. Additionally, clinician visits to patients at the end of life are associated with improved outcomes such as decreased risk of hospitalization, emergency department visits, and hospital death; and higher satisfaction with care.^{3,4,5}

While these interactions are valued by caregivers, one prior study found that nearly 29% of patients receiving routine hospice care in home settings did not receive a skilled visit from a social worker, therapist, or nurse in the final days of life.⁶ A recent analysis of Medicare claims data by RTI showed that in the final 7 days of life, nearly 97% of patients received at least one visit from hospice staff, including skilled nurses, medical social workers, aides, therapists, and physicians (Figure 1).

Figure 1. Percentage of Patients Receiving a Visit from a Given Discipline in the Final 7 Days and the Final 3 Days of Life



Source: RTI analysis of hospice claims for all Medicare hospice patients who died under hospice care in 2014 (n= 973,069 patients).

Most patients (92.4%) received at least one skilled nursing visit in the last 7 days of their life, and many patients (45.6%) received at least one visit from a medical social worker. When the time frame was limited to the final 3 days of life (Figure 1), the analysis showed that both the proportion of patients receiving a visit and the average number of visits decreased. In the final 3 days of life, 85.2% of patients received at least one skilled nursing visit. Additionally, there is significant large variation across patients in the number of visits received at the end of life. RTI's analyses show that 6% of patients did not receive a visit from any discipline in the final 3 days of life, whereas more than 10% received at least 7 visits. Information on this variation could help patients and families as they select a hospice.

When public reporting begins, will current quality measures provide consumers with meaningful information to distinguish between high-quality and low-quality providers?

Public reporting of the seven measures currently included in the CMS Hospice Quality Reporting Program is slated to begin in the near future, although no date has been specified for its launch.⁷ What is the extent to which these measures are likely to help consumers as they select a provider?

For six of the seven existing measures in the Hospice Quality Reporting Program, all of which capture individual care processes, average hospice performance scores are 90% or higher. In other words, most patients receive individual care processes that are recommended as part of high-quality care at admission. For example, on average, nearly 93% of patient stays in a hospice had documentation showing that the patient received a pain screening at admission. The exception to this pattern is for the pain assessment quality measure: on average, approximately 66% of patients received a comprehensive pain assessment within 1 day of screening positive for experiencing pain.

Although this generally high performance on individual measures is an encouraging finding, the measures have two limitations that will affect their utility for consumers. First, the limited variation in quality scores between hospices makes the measures less useful for consumers. Low variation in scores limits the ability to distinguish those hospices providing higher quality care from those providing lower quality care. On the other hand, even measures with low variation will reveal some hospices that perform poorly, which should alert consumers as they select a provider.

A second limitation is that the measures do not provide consumers with an indication of the overall quality of a hospice. For example, patients and families may find

it challenging to interpret the seven separate process measures if a hospice performs well on some quality measures but not on others, especially when all of these measures reflect care processes that should be completed for all patients upon admission.

While hospices scored high on individual care process quality measures, our analysis shows that, on average, only about 68% of patient stays in a hospice had documentation that all of the seven recommended care processes were performed at admission. This finding suggests that a quality measure that combines these minimal components of a thorough patient assessment at admission may be a useful and clear way to convey to patients and families the quality of care a hospice provides. A composite measure addressing comprehensive assessment around admission is being developed by CMS and RTI.

What new measures are needed to assess hospice quality and support patient decision-making?

Future Directions for Assessing Quality of Care Near Death

Despite the critical role of high-quality hospice care in ameliorating patient symptoms and caregiver concerns near death, no existing quality measures assess care at or near the time of death. When death is imminent and hospice care intensifies, the appropriate focus of hospice staff should be on providing patient care, rather than administering standardized patient-level data collection efforts. Given this challenge, Medicare claims data gathered could be leveraged for quality measurement without burdening patients and caregivers or interfering with care processes around the time of death. However, claims data do not currently reflect visits made by all members of the interdisciplinary hospice care team; consequently, these data cannot provide a full picture of the frequency and types of care and support that patients and caregivers receive in the last days of life.

To fill this measurement gap, CMS and RTI are developing quality measures that will assess the frequency and types of visits provided by hospice at the end of life. The measure set under development will use data collected on the Hospice Item Set V2.00.0^b and includes two measures. The first measure will assess the percentage of patients receiving at least one visit from registered nurses, physicians, nurse practitioners, or physician assistants in the last 3 days of life, addressing case management and clinical care. The second measure will assess the percentage of patients receiving at least two visits from medical social workers, chaplains or spiritual counselors, licensed practical nurses, or hospice aides in the last 7 days of life.

^b New items will be collected via the Hospice Item Set V2.00.0 in 2017.

This measure accounts for the need for providers to offer individualized care that is in line with the patient's and family's preferences and goals for care and contributes to the overall well-being of the patient and family. Taken together, these two measures reflect hospice's holistic care approach and will support consumers in selecting a hospice when services are needed.

Additionally, CMS began collecting data using the CAHPS Hospice Survey in early 2015, assessing caregiver and family experience of care in areas such as communication and care coordination.⁸ The survey will provide important insight into hospices' ability to deliver care to the entire patient and family unit, and it will reflect the cumulative experience of families because it is administered after death. Although it will not directly capture the patient's voice, this survey will provide insight into how families experience hospice care.

Concerns Regarding Quality of Care in Hospices with High Live Discharge Rates

After variable lengths of stay, more than 80% of patients are discharged from hospice when they die. However, a small but increasing proportion of patients are discharged alive. Measuring quality of care both for patients who die under hospice care and for those who are discharged alive from hospices is important for supporting consumer choice. Because of clinical uncertainty, a small proportion of live discharges from hospices is to be expected. However, a disproportionately high rate of live discharges could be concerning, potentially indicating that some patients were not appropriate candidates for hospice care at the time of admission.

Studies using existing administrative data show that about one-third of live discharges from hospice were initiated by patients and families, for reasons such as patients revoking the hospice benefit or moving out of the hospice's service area.⁹ However, two findings may indicate quality concerns. First, discharges that occur near the end of a patient's eligibility for hospice benefits could indicate hospices' attempts to avoid the heightened scrutiny applied to hospices that have a high proportion of patients with very long stays. Such discharges may also indicate hospices' efforts to reduce their risk of reaching the CMS cap on the total payment a hospice can receive in a given year. Second, some reasons for discharge, such as patient revocation of the hospice benefit, might signal patient and family dissatisfaction with quality of care, or hospice efforts to avoid providing high-cost and intensive care for patients.

Live discharges are not distributed evenly across hospices. For example, analysis of the hospice-level live discharge rate in 2012 found that the mean hospice-level live discharge rate was nearly 19%, and 10% of hospices had 40% or more of their stays discharged alive.⁶ This provides a compelling reason to look more closely at the motivation and explanations for live discharges and to consider the development of one or more quality measures to inform consumer choice.

As part of an assessment of live discharges, RTI conducted a study using national patient-level data from the Hospice Item Set to examine whether live discharge rates are related to the quality of care patients receive. The preliminary findings suggest that in hospices with a higher rate of live discharges, patients were less likely to receive some critical care processes around admission, including discussion of treatment preferences, discussion of beliefs and values, screening and treatment for shortness of breath, and bowel regimens. We are continuing to investigate the relationship between quality of care around admission and live discharges at the patient level, focusing on the reason for live discharge and the relationship to length of stay.

Discussion

Hospices provide holistic end-of-life care for an increasing number of patients, and their families, in a variety of settings. The rapid growth of the hospice industry and the increasing number of patients and families who access hospice care has created a pressing need for insight into the quality of hospice care. Quality metrics are important for a variety of stakeholders—including consumers, providers, CMS, and other payers—particularly in light of attempts to reform the payment system for post-acute and long-term care, including hospice care.

RTI has been analyzing national quality measure data submitted by hospices to CMS since 2014, and the findings suggest room for improvement in the delivery of critical care processes at hospice admission. Additionally, these findings confirm previous research showing that some patients receive few or no visits as they near death. Finally, our preliminary evidence suggests that live discharge from hospice may be correlated with poor care delivery at admission.

Measure development efforts to address these specific quality concerns are underway. However, measure development for hospice continues to be challenging, partly because gathering and reporting information on quality of care in a manner that is respectful of patients and families at a highly vulnerable time is difficult.

Consequently, a gap persists in quality measures, particularly patient-reported outcome measures, despite a high level of desire for such measures on the part of patients, families, and policymakers.

Further, some aspects of high-quality hospice care are extremely difficult to capture using available data sources. For example, one tenet of hospice care is the provision of care that is congruent with patients' stated preferences and responsive to changing patient care needs and preferences. However, preliminary attempts to collect patient-level data, which are necessary to examine this aspect of quality of care, have proven to be highly burdensome to patients, caregivers, and hospice providers. Consequently, some aspects of care—perhaps those most critical to high-quality hospice care—are the most elusive to measure.

RTI is continuing to research the quality of end-of-life care provided in hospice. Our findings will help inform the critical national discourse about what constitutes high-quality care near the end of life and ultimately help improve end-of-life care and support provided to American patients and their families.

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