

SQAC Quality Priority Proposal

Proposed Priority Area: End of Life Care

Description of the priority area: End of life care is the support and medical care given to patients during the time surrounding death. This includes decisions about medical treatments, hospitalizations, admissions to skilled nursing facilities, palliative care and hospice as well as patient and family decision making.

Reasons it is being highlighted: There is significant variation in the amount of intervention and cost of care near the end of a patient's life.¹ Often interventions are costly and do little to improve a patient's chance for sustained improvement in their condition in the mid to long term. Palliative and end of life care programs can help improve the quality of care that patients experience throughout the course of their illness.² In addition to improving the patient's comfort, these programs can reduce spending on interventions and treatments that will not appreciably improve a patient's condition or quality of life and may also result in reduced emergency department visits and fewer preventable hospitalizations.

Ways that quality may be improved: Patients can make their wishes known to their families and loved ones through advanced directives. Providers can counsel patients and their families on the probable course of their illness and explain the choices for treatment, including being clear on when further treatment is likely to have little benefit and be traumatic for the patient.

Ways that quality could be measured: There are several measures focused on end of life care.

SQMS

The following measures addressing end of life care are included in the SQMS:

- Proportion admitted to hospice for less than 3 days
- Advance Care Plan
- Pain Screening
- Pain Assessment
- Palliative and End of Life Care: Dyspnea Screening & Management
- Dyspnea Screening
- Dyspnea Treatment
- Beliefs/Values Addressed

¹ Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life - See more at: <http://iom.nationalacademies.org/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx#sthash.0hjAKHdI.dpuf>

² http://www.qualityforum.org/Topics/Palliative_Care_and_End-of-Life_Care.aspx

While not currently measured through the SQMS, it is possible to measure the number patients who receive end of life counseling services.

NQF Measures

In 2012 NQF endorsed the following 14 evidence-based quality measures for palliative and end-of-life care which are listed below. CMS requires Hospices to submit data on the Hospice Item Set, which collects data on seven of these measures which are indicated by a star * below.

- pain screening, for hospice and palliative care (NQF #1634)*;
- pain assessment, for hospice and palliative care (NQF #1637)*;
- patients treated with an opioid who are given a bowel regimen (NQF #1617)*;
- patients with advanced cancer assessed for pain at outpatient visits (NQF #1628);
- dyspnea treatment, for hospice and palliative care (NQF #1638)*;
- dyspnea screening, for hospice and palliative care (NQF #1639)*;
- patients admitted to an intensive care unit who have care preferences documented (NQF #1626);
- treatment preferences, for hospice and palliative care (NQF #1641)*;
- percentage of hospice patients with documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss such concerns (NQF #1647)*³;
- comfortable dying (NQF #0209);
hospitalized patients who die an expected death with an implantable cardioverter defibrillator (ICD) that has been deactivated (NQF #1625)
- family evaluation of hospice care (NQF #0208);
- Consumer Assessments and Reports of End of Life (NQF #1632);
- bereaved family survey (NQF #1623).

Starting in 2015, in addition to the Hospice Item Set quality reporting requirements listed above, CMS will require that hospices administer the Hospice Experience of Care Survey, which will gather information from caregivers of deceased hospice patients about patient and family experiences with hospice care. The CAHPS Hospice Survey consists of 47 questions and is administered to the primary informal caregiver of the decedent who died while receiving hospice care. The Appendix provides a list of questions included in the survey.

Cross Cutting Dimensions

The SQAC believes it is important to consider end of life care across a number of dimensions including disparities, transparency, care coordination and patient experience/activation.

³ The Hospice Item Set measure is beliefs/values addressed (if desired by the patient) which is modified from NQF #1647.

Ways that disparities in end of life care could be measured and improved: Measures described above can be stratified by race/ethnicity, income, geography, and age. Performance improvements can then be targeted to particular providers or geographies in order to reduce disparities in care.

Improving transparency: By providing measurement of end of life care, there will be increased visibility into additional adoption of advanced directives by patients and additional end of life care planning. Reporting of quality measures for hospices could help patients make informed comparisons across facilities.

Link to care coordination: At the end of life patients are often cared for by a diverse array of specialists who in many cases do not have complete information about the patient's medical history. Further complicating the situation is that patients and family members often have to make quick decisions without complete information about treatment options. Care coordination can help providers to have and deliver appropriate patient information, so that patients and their families are able to express their wishes and that they are taken into account. Care coordination can also help exchange appropriate information between caregivers in hospitals, skilled nursing facilities and hospice as appropriate.

Patient experience/patient activation: For end of life care, patient experience and caregiver experience is the fundamental measure of quality. Care giver experience is being measured by the Hospice Experience of Care survey which is administered to a family care giver after a patient's death. This survey is described in more detail in the Appendix. Patient activation is necessary to engage patients in making deep decisions about their health, their quality of life and the course of their death. To achieve this, it is frequently necessary to provide ongoing, active counseling. One way to measure the impact of this counseling would be to measure the number of patients who report having drafted an advanced directive describing their wishes for end of life care.

State Actors Who Are Working in this Area: DPH,⁴⁵ EOEAE

⁴ <http://commonhealth.wbur.org/2014/12/massachusetts-end-of-life-counseling>

⁵ http://molst-ma.org/sites/molst-ma.org/files/UMASS_MAEExpertPanelEndofLife_3-2015.pdf

Appendix

CAHPS Hospice Survey Quality Measures and Constituent Items

The Centers for Medicare & Medicaid Services (CMS) implemented the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospice Survey to measure the experiences that patients and their caregivers have with hospice care. The survey was developed to provide a source of information from which selected measures could be publicly reported to patients and their family members as a decision aid for selection of a hospice program, to aid hospices with their internal quality improvement efforts and external benchmarking with other facilities, and provide CMS with information for monitoring the quality of care provided. It was first administered in 2015. In measuring performance, the survey groups some questions into composites, while others remain as single-subject questions, as shown below.

Composite Measures

- Hospice Team Communication
 - While your family member was in hospice care, how often did the hospice team keep you informed about when they would arrive to care for your family member?
 - While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?
 - How often did the hospice team listen carefully to you when you talked with them about problems with your family member's hospice care?
 - While your family member was in hospice care, how often did the hospice team keep you informed about your family member's condition?
 - While your family member was in hospice care, how often did the hospice team listen carefully to you?
- Getting Timely Care
 - While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?
 - How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?
- Treating Family Member with Respect
 - While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?
 - While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?
- Providing Emotional Support

- While your family member was in hospice care, how much emotional support did you get from the hospice team?
- In the weeks after your family member died, how much emotional support did you get from the hospice team?
- Getting Help for Symptoms
 - Did your family member get as much help with pain as he or she needed?
 - How often did your family member get the help he or she needed for trouble breathing?
 - How often did your family member get the help he or she needed for trouble with constipation?
 - How often did your family member get the help he or she needed from the hospice team for feelings of anxiety or sadness?
- Getting Hospice Care Training
 - Did the hospice team give you the training you needed about what side effects to watch for from pain medicine?
 - Did the hospice team give you the training you needed about if and when to give more pain medicine to your family member?
 - Did the hospice team give you the training you needed about how to help your family member if he or she had trouble breathing?
 - Did the hospice team give you the training you needed about what to do if your family member became restless or agitated?

Single Item Measures

Providing Support for Religious and Spiritual Beliefs

- Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?

Information Continuity

- While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member's condition or care?

Understanding the Side Effects of Pain Medication

- Side effects of pain medicine include things like sleepiness. Did any member of the hospice team discuss side effects of pain medicine with you or your family member?

Global Measures

Overall Rating of Hospice

- Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member's hospice care?

Recommend Hospice

- Would you recommend this hospice to your friends and family?