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Geriatrics and Palliative Care, Fall 2019 Cycle Track 2: CDP Report

TECHNICAL REPORT
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Contents

Executive Summary

Factors such as the aging United States (U.S.) population, the projected increases in the number of Americans with chronic illnesses, disabilities, and functional limitations, and increases in ethnic and cultural diversity, have intensified the importance of improving the quality of palliative and end-of-life care, and geriatric care, with an emphasis on the need for individualized, person-centered care.[1] To date, the National Quality Forum (NQF) has endorsed more than 30 measures that address geriatric care, palliative care, and end-of-life care. These measures address physical, spiritual, and legal aspects of care, as well as the care of patients nearing the end of life.

Due to circumstances around the COVID-19 global pandemic, commenting periods for all measures evaluated in the fall 2019 cycle were extended from 30 days to 60 days. Based on the comments received during this 60-day extended commenting period, measures entered one of two tracks. If the comments received required a post-comment meeting, the measures were moved to *Track 2* and deferred to the spring 2020 cycle. All other measures continued on *Track 1* as part of the fall 2019 cycle.

Track 1: In the fall 2019 cycle, the Standing Committee evaluated one measure undergoing maintenance review against the NQF's standard evaluation criteria. The Standing Committee recommended the measure for continued endorsement. The Consensus Standards Approval Committee (CSAC) did not uphold the Standing Committee's recommendation and the measure will be reconsidered by the Standing Committee during the fall 2020 cycle. The CSAC did not uphold the Standing Committee's recommendation due to concerns with how the validity and use criteria were applied.

Measure Not Endorsed:

- **NQF #1623** Bereaved Family Survey

Track 2: One measure undergoing maintenance review was deferred to the spring 2020 cycle. The Standing Committee recommended the measure for continued endorsement. The measure was endorsed by the CSAC.

Measure Endorsed:

- **NQF #2651** CAHPS® Hospice Survey (experience with care)

This report contains details of the evaluation of measure assigned to *Track 2* and moved to the spring 2020 cycle. Detailed summaries of the Standing Committee's discussion and ratings of the criteria for this measure are in Appendix A. The detailed evaluation summary of the measure assigned to *Track 1* and that remained in the fall 2019 cycle is included in a separate report titled Geriatrics and Palliative Care, Fall 2019 Cycle Track 1: CDP Report.

Introduction

Improving the quality of both palliative and end-of-life care, and geriatric care more generally, is becoming increasingly important due to factors that have intensified the need for individualized, person-centered care. Some of these factors include the aging U.S. population; the projected increases in the number of Americans with chronic illnesses, disabilities, and functional limitations; and increases in ethnic and cultural diversity.[1] In 2018, the 65-and-older population numbered 50.9 million individuals (15.6 percent of the U.S. population), and this figure is expected to increase to 94.7 million by 2060.[2] As many as 35 percent of older Americans have some type of disability (e.g., vision, hearing, ambulation, cognition), while 46 percent of those 75 and older report limitations in physical functioning.[3] Additionally, data indicate that 46 percent of the noninstitutionalized U.S. population aged 65 or older have two or three chronic conditions, and 15 percent have four or more.[4]

Palliative care is patient- and family-centered care that optimizes quality of life by anticipating, preventing, and alleviating suffering throughout the continuum of a person's illness by addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice.[5] Palliative care is holistic, thus requiring an interdisciplinary, team-based approach to care. With its focus on improving quality of life, palliative care is distinct from care intended to cure an illness or condition; although, it can be delivered concurrently with curative therapies and can begin at any point in the disease progression. It can be provided in any setting, including outpatient care settings and at home.

Although palliative care is still provided primarily by specially trained teams of professionals in hospitals and through hospice, there is increased focus on provision of palliative care in the community,[6] often by clinicians who are not palliative care specialists. The provision of palliative care has been shown to increase patient and family satisfaction with care,[7] reduce emergency department visits, hospital admissions, and hospital readmissions,[8] and decrease costs to the healthcare system.[9,10] However, access to hospital-based specialty palliative care continues to vary by hospital size and location, and even when programs are available, not all patients who could benefit actually receive those services.[11]

Palliative care is appropriate for those who are expected to recover, as well as for those who have chronic, progressive, and/or terminal illness. For those with a terminal illness, high quality end-of-life care is comprehensive care that addresses medical, emotional, spiritual, and social needs during the last stages of illness.[12] Much end-of-life care is palliative, when life-prolonging interventions are no longer appropriate, effective, or desired.[13] Thus, for patients nearing the end of life, there often will be a greater emphasis on palliative care over curative treatment. In many instances, this care is provided in the form of hospice.

Hospice is a service delivery system that relies on an interdisciplinary approach that emphasizes symptom management for patients near the end of life. While hospice care is covered through Medicaid and most private insurance plans, approximately 85 percent of hospice enrollees receive coverage through the Medicare hospice benefit.[14] Almost 1.5 million Medicare beneficiaries and their families received hospice care in 2017.[15] For these individuals, the average length of stay was 76.1 days; however, the median length of stay was only 24 days, meaning that many enrolled in hospice too late to fully realize the benefits of the program.[16] Beginning in 2014, Medicare-certified hospices were required to report performance on quality measures as part of the Hospice Quality Reporting Program (HQRP); those not reporting face a reduction in payments from Medicare. Performance rates for these measures are publicly reported on the Centers for Medicare & Medicaid Services (CMS) Care Compare website.[17]

Since 2006, when it first developed a measurement framework for palliative and end-of-life care and endorsed 38 evidence-based preferred practices for high quality palliative care programs,[18] NQF has endorsed more than 30 measures in this topic area, many of which currently are used in federal quality improvement and public reporting programs.

In 2017, NQF expanded the scope of the Standing Committee charged with the oversight of the palliative and end-of-life care measures portfolio by adding measures specifically relevant to older adults (i.e., the geriatric population). Several previously seated and new members of this renamed Geriatrics and Palliative Care Standing Committee are geriatric healthcare professionals. Thus, the Standing Committee has the requisite expertise to assume oversight of measures that focus on key issues specific to older adults, such as multimorbidity and frailty. At present, measures specifically relevant to the geriatric population remain aspirational. Thus, for the time being, the geriatrics measures evaluated by this Standing Committee include setting-specific measures that primarily affect older individuals. Examples of such measures include those that assess care provided by home health agencies or other home-based care providers.

NQF Portfolio of Performance Measures for Geriatrics and Palliative Care Conditions

The Geriatrics and Palliative Care Standing Committee (Appendix C) oversees NQF's portfolio of Geriatrics and Palliative Care measures (Appendix B). This portfolio contains 35 measures, including one measure that comprised eight patient-reported outcome measures: 17 process measures, 17 outcome measures, and one composite measure (see table below).

Table 1. NQF Geriatrics and Palliative Care Portfolio of Measures

	Process	Outcome	Composite
Palliative/End-of-Life Care			
Physical Aspects of Care	8	0	0
Psychological and Psychiatric Aspects of Care	0	0	0
Social Aspects of Care	0	0	0
Spiritual, Religious, and Existential Aspects of Care	1	0	0
Cultural Aspects of Care	0	0	0
Care of the Patient Nearing the End of Life	3	12	1
Ethical and Legal Aspects of Care	3	0	0
Geriatrics	2	5	0
Total	17	17	1

Some of the measures in the Geriatrics and Palliative Care portfolio will be evaluated by other NQF Standing Committees. These include a cultural communication measure (Patient Experience and Function Committee) and pain measures for cancer patients (Cancer Committee).

Geriatrics and Palliative Care Measure Evaluation

On February 20 and 25, 2020, the Geriatrics and Palliative Care Standing Committee evaluated two measures undergoing maintenance review against NQF's standard measure evaluation criteria. The Standing Committee reached and maintained quorum during both meetings. The detailed evaluation summary of the one measure assigned to *Track 2* and deferred to the spring 2020 cycle is included in this report. The detailed evaluation summary of the measure assigned to *Track 1* and that remained in the fall 2019 cycle is included in a separate report titled Geriatrics and Palliative Care, Fall 2019 Cycle Track 1: CDP Report.

Table 2. Geriatrics and Palliative Care Measure Evaluation Summary, Fall 2019 Track 2

	Maintenance	New	Total
Measures reviewed	1	0	1
Measures endorsed	1	0	1

Comments Received Prior to Standing Committee Evaluation

NQF solicits comments on endorsed measures on an ongoing basis through the Quality Positioning System (QPS). In addition, NQF accepts comments for a continuous 16-week period during each evaluation cycle via an online tool located on the project webpage. For this evaluation cycle, the commenting period opened on December 11, 2019. No comments were submitted prior to the measure evaluation meetings.

Comments Received After Standing Committee Evaluation

Considering the recent COVID-19 global pandemic, many organizations needed to focus their attention on the public health crisis. To provide greater flexibility for stakeholders and continue the important work in quality measurement, NQF extended commenting periods and adjusted measure endorsement timelines for the Fall 2019 Cycle.

Commenting periods for all measures evaluated in the Fall 2019 cycle were extended from 30 days to 60 days. Based on the comments received during this 60-day extended commenting period, measures entered one of two tracks:

> **Track 1: Measures Continuing in Fall 2019 Cycle**
> **Measures that did not receive public comments or only received comments in support of the Standing Committees' recommendations** moved forward to the Consensus Standards Approval Committee (CSAC) for review and discussion during its meeting on July 28-29, 2020.
>
> - **Exceptions**
>   Exceptions were granted to measures if non-supportive comments received during the extended post-comment period were similar to those received during the pre-evaluation meeting period and have already been adjudicated by the respective Standing Committees during the measure evaluation Fall 2019 meetings.

> **Track 2: Measures Deferred to Spring 2020 Cycle**
> **Fall 2019 measures requiring further action or discussion from a Standing Committee were deferred to the Spring 2020 cycle.** This included measures where consensus was not reached or those that required a response to public comments received. Measures undergoing maintenance review retained endorsement during that time.

During the Spring 2020 CSAC meeting on November 17-18, 2020, the CSAC reviewed all measures assigned to Track 2. A list of measures assigned to Track 1 can be found in the Executive Summary section of this report for tracking purposes, but these measures were reviewed during the Fall 2019 CSAC review period.

The extended public commenting period with NQF member support closed on May 28, 2020. Following the Standing Committee's evaluation of the measures under review, NQF received one comment from one organization pertaining to the draft report and to the measure under review. The comment for the measure under review was discussed at the July 9, 2020 post-comment meeting and have been summarized in Appendix A.

Throughout the extended public commenting period, NQF members had the opportunity to express their support ("support" or "do not "support") for each measure submitted for endorsement consideration to inform the Standing Committee's recommendations. No NQF members provided their expression of support or non-support.

Summary of Measure Evaluation: Fall 2019 Measures, Track 2

#2651 CAHPS® Hospice Survey (experience with care) (Centers for Medicare & Medicaid Services): Endorsed

Description: The measures submitted here are derived from the CAHPS® Hospice Survey, which is a 47-item standardized questionnaire and data collection methodology. The survey is intended to measure the care experiences of hospice patients and their primary caregivers. Respondents to the survey are the primary informal caregivers of patients who died under hospice care. These are typically family members but can be friends. The hospice identifies the primary informal caregiver from their administrative records. Data collection for sampled decedents/caregivers is initiated two months following the month of the decedent's death; **Measure Type**: Outcome: PRO-PM; **Level of Analysis**: Facility; **Setting of Care**: Other; **Data Source**: Instrument-Based Data

In 2017, nearly 1.5 million Medicare beneficiaries received hospice services, with nearly $18 billion spent on Medicare hospice expenditures. Variation has been reported across hospices regarding processes of care associated with care quality. Evidence of variation in hospice care processes points to the need for performance measures that can be systematically implemented to monitor hospice performance and make fair comparisons across facilities. The Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Hospice Survey was created to ensure that an assessment of the patient- and family-centeredness of care would be included to monitor hospice performance, promote quality improvement, and inform consumer decision making in the selection of a hospice via public reporting of results.

Prior to the Standing Committee meeting, this measure was reviewed by the NQF Scientific Methods

Panel (SMP). The SMP passed the measure with a moderate rating for reliability and a moderate rating for validity.

The Standing Committee agreed there was no change in evidence from previous endorsement and agreed to accept the previous decision and to vote from the measure's previous review cycle, which was that the measure passes the evidence criterion. The Standing Committee felt that there is a clear performance gap that warrants a national performance measure. The Standing Committee and the developer had a robust discussion around exclusions, examining ways to include as many types of patients and perspectives as possible. The current survey is completed by informal caregivers. The Standing Committee noted that the survey captures the caregiver's perspective on the quality of care received by the patient. Patients may have a different perspective than caregivers, and patients without informal caregivers are currently not represented in the survey results. The Standing Committee also noted that caregivers for pediatric hospice patients are excluded from the survey and felt this was a major gap in measurement for hospice care. It was noted that caregivers for pediatric patients are usually the patient's parents and that there may be fundamental differences between parents and informal caregivers as populations to be surveyed. The developer stated they would want to reexamine the survey from the beginning for the pediatric caregiver population to ensure it was appropriate, valid, and reliable. They felt a separate survey would be needed as opposed to stratified results from this one. The Standing Committee was satisfied with the reliability and validity of this measure and unanimously accepted the SMP's rating of moderate in those categories.

The Standing Committee had questions related to the number of items in the survey, the methods of completion, and how providers could communicate about the survey—all targeted towards survey feasibility and increasing survey completion rates. The developer noted that they are working on reducing the number of questions on the survey. The Standing Committee wondered if an option to complete the survey electronically would increase responses, and the developer responded that they are working on testing electronic response across all CAHPS® surveys. The Standing Committee agreed that the measure met the feasibility criterion. The Standing Committee had a brief and positive discussion around the use and usability criteria. They noted the measure is in use in the Hospice Quality Reporting Program and that the results are available on Care Compare. Standing Committee members shared that their organizations carefully reviewed results on this measure and actively worked to improve care to improve measure performance. Standing Committee members also reported using the results on Care Compare to find hospice care both for patients and family members. They stated that they found the results of this measure personally useful.

The CSAC expressed no concerns and upheld the Standing Committee's recommendation for continued endorsement.

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Appendix A: Details of Measure Evaluation

Rating Scale: H=High; **M**=Moderate; **L**=Low; **I**=Insufficient; **NA**=Not Applicable

Vote totals may differ between measure criteria and between measures as Standing Committee members often have to join calls late or leave calls early. NQF ensures that quorum is maintained for all live voting. All voting outcomes are calculated using the number of Standing Committee members present for that vote as the denominator.

Measure Endorsed

#2651 CAHPS® Hospice Survey (experience with care)

Submission **|** Specifications

Description: The measures submitted here are derived from the CAHPS® Hospice Survey, which is a 47-item standardized questionnaire and data collection methodology. The survey is intended to measure the care experiences of hospice patients and their primary caregivers. Respondents to the survey are the primary informal caregivers of patients who died under hospice care. These are typically family members but can be friends. The hospice identifies the primary informal caregiver from their administrative records. Data collection for sampled decedents/caregivers is initiated two months following the month of the decedent's death.

The publicly reported measures described here include the following six multi-item measures.

- Hospice Team Communication
- Getting Timely Care
- Treating Family Member with Respect
- Getting Emotional and Religious Support
- Getting Help for Symptoms
- Getting Hospice Training

In addition, there are two global rating items that are publicly-reported measures.

- Rating of the hospice care
- Willingness to recommend the hospice

Below we list each multi-item measure and its constituent items, along with the two global rating items. Then we briefly provide some general background information about CAHPS® surveys.

List of CAHPS® Hospice Survey Measures

Multi-Item Measures

Hospice Team Communication (Composed of 6 items)

+ 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?

+ 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?

Getting Timely Care (Composed of 2 items)

+ 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?

#2651 CAHPS® Hospice Survey (experience with care)

Treating Family Member with Respect (Composed of 2 items)

+ 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 (Composed of 3 items)

+ 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?

+ 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?

Getting Help for Symptoms (Composed of 4 items)

+ 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 receive the help he or she needed from the hospice team for feelings of anxiety or sadness?

Getting Hospice Care Training (Composed of 5 items)

+ Did the hospice team give you enough training 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?

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

Global Rating Measures:

In addition to the multi-item measures, there are two “global” ratings measures. These single-item measures provide families and patients looking for care with overall evaluations of the care provided by the hospice. The items are rating of hospice care and willingness to recommend the hospice.

+ Rating of Hospice Care: 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?

+ Willingness to Recommend Hospice: Would you recommend this hospice to your friends and family?

The CAHPS® Hospice Survey is part of the CAHPS® family of experience of care surveys. English and other translations of the survey are available at http://www.hospicecahpssurvey.org/en/survey-instruments/ . CMS initiated national implementation of the CAHPS® Hospice Survey in 2015. Hospices meeting CMS eligibility criteria were required to administer the survey for a “dry run” for at least one month of sample from the first quarter of 2015. Beginning with the second quarter of 2015, hospices are required to participate on an ongoing monthly basis in order to receive their full Annual Payment Update from CMS. Information regarding survey content and national implementation requirements, including the latest versions of the survey instrument and standardized protocols for data collection and submission, are available at: http://www.hospicecahpssurvey.org/. Public reporting of the survey-based measures on Hospice Compare started in February 2018 (www.medicare.gov Choose find hospice care)

A list of the CAHPS® Hospice Survey measures, including the components of the multi-item measures can be found in Appendix A

#2651 CAHPS® Hospice Survey (experience with care)

Numerator Statement: CMS calculates CAHPS® Hospice Survey measure scores using top-, middle- and bottom-box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response(s). The bottom box score refers to the percentage of caregiver respondents that give the least positive response(s). The middle box is the proportion remaining after the top and bottom boxes have been calculated; see below for details. Details regarding the definition of most and least positive response(s) are noted in Section S.5 below.

Denominator Statement: CAHPS® Hospice Survey measure scores are calculated only for hospices that had at least 30 completed questionnaires over the most recent eight quarters of data collection.

The target population for the survey are the adult primary caregivers of hospice decedents. Respondent eligibility and exclusions are defined in detail in the sections that follow. A survey is defined as completed when at least 50 percent of the questions applicable to all decedents/caregivers are answered (Questions 1 – 4, 6 – 13, 15, 17, 21, 24, 26, 28, 30 – 32, and 35 – 47). The survey uses screener questions to identify respondents eligible to respond to subsequent items. Therefore, denominators vary by survey item (and corresponding multi-item measures, if applicable) according to the eligibility of respondents for each item. In addition, for the Getting Hospice Care Training measure, scores are calculated only among those respondents who indicate that their family member received hospice care at home or in an assisted living facility.

Exclusions: The eight measures included here are calculated only for hospices that have at least 30 completed surveys over eight quarters of data collection.

The exclusions noted in here are those who are ineligible to participate in the survey. The one exception is caregivers who report on the survey that they “never” oversaw or took part in the decedent’s care; these respondents are instructed to complete the “About You” and “About Your Family Member” sections of the survey only.

Cases are excluded from the survey target population if:

- The hospice patient is still alive
- The decedent’s age at death was less than 18
- The decedent died within 48 hours of his/her last admission to hospice care
- The decedent had no caregiver of record
- The decedent had a caregiver of record, but the caregiver does not have a U.S. or U.S. Territory home address
- The decedent had no caregiver other than a nonfamilial legal guardian
- The decedent or caregiver requested that they not be contacted (i.e., by signing a no publicity request while under the care of hospice or otherwise directly requesting not to be contacted)
- The caregiver is institutionalized, has mental/physical incapacity, has a language barrier, or is deceased
- The caregiver reports on the survey that he or she “never” oversaw or took part in decedent’s hospice care

Adjustment/Stratification: Statistical risk model

Level of Analysis: Facility

Setting of Care: Other

Type of Measure: Outcome: PRO-PM

Data Source: Instrument-Based Data

Measure Steward: Centers for Medicare & Medicaid Services

STANDING COMMITTEE MEETING February 20, 2020 and February 25, 2020

1. Importance to Measure and Report: <u>The measure meets the Importance criteria.</u>

(1a. Evidence; 1b. Performance Gap)

1a. Evidence: **No vote**; 1b. Performance Gap: **H-8**; **M-10**; **L-0**; **I-0**

<u>Rationale</u>:

- During the prior review in 2016, as evidence for this measure, the developer provided a table linking multiple processes or structures of care to the outcomes captured in the eight measures that are derived from the Hospice CAHPS® survey. The developer also summarized results from focus groups and individual interviews with family members of hospice decedents who reviewed the survey and supported its contents. The Standing Committee agreed there was no change in evidence from the

#2651 CAHPS® Hospice Survey (experience with care)

previous NQF evaluation. The Standing Committee agreed there is no need for repeat vote on Evidence.

- The developer provided performance data from 2,933 hospice agencies that had at least 30 respondents in the third quarter of 2016 to the second quarter in 2018. Mean measures scores ranged from 75.1 (Standard Deviation (SD) =6.0) for “Getting help for symptoms” to 90.5 (SD=3.9) for “Treating family member with respect.”
- The developer presented 2015-2016 CAHPS® Hospice Survey data (including *CAHPS® Hospice Survey* measure scores by age, gender, race, ethnicity, education, and caregiver respondent language), noting potential racial and ethnic disparities in the experience of care measures.
- The Standing Committee agreed that variation in agency scores for each measure indicates a performance gap exists. Members also noted that the disparities data were particularly compelling, given the direction of the identified disparities varies across the measures.

2. Scientific Acceptability of Measure Properties: <u>The measure meets the Scientific Acceptability criteria.</u>

(2a. Reliability precise specifications, testing; 2b. Validity testing, threats to validity)

2a. Reliability: **Yes-18; No-0**; 2b. Validity: **Yes-18; No-0**

<u>Rationale</u>:

- This measure was reviewed by SMP subgroup members who found the eight patient-reported outcome performance measures (PRO-PMs) included under #2651 to be reliable and valid.
- The SMP’s ratings for Reliability: H-2, M-4, L-0, I-0
- The SMP’s ratings for Validity: H-0, M-6, L-0, I-0
- The Standing Committee and the developer had a robust discussion around exclusions, examining ways to include as many types of patients and perspectives as possible. The current survey is completed by informal caregivers. The Standing Committee noted that the survey captures the caregiver’s perspective on the quality of care received by the patient. Patients may have a different perspective than caregivers, and patients without informal caregivers are currently not represented in the survey results.
- Both the Standing Committee and the developer agreed that surveying patients during their final days could be viewed as intrusive and could add to the patient’s suffering. There was agreement that capturing the patient’s perspective could be useful for care improvement but no agreement on how to best obtain this information.
- The Standing Committee also noted that caregivers for pediatric hospice patients are excluded from the survey. It was noted that caregivers for pediatric patients are usually the patient’s parents and that there may be fundamental differences between parents and informal caregivers as populations to be surveyed.
- The Standing Committee felt this was a major gap in measurement for hospice care. The developer stated they would want to start over and reexamine the survey from the beginning for the pediatric caregiver population to ensure it was appropriate, valid, and reliable. They felt a separate survey would be needed as opposed to stratified results from this survey.
- The Standing Committee was satisfied with the reliability and validity of this measure and unanimously accepted the Scientific Methods Panel rating of moderate for both criteria.

3. Feasibility: H-2; M-16; L-0; I-0

(3a. Clinical data generated during care delivery; 3b. Electronic sources; 3c. Susceptibility to inaccuracies/ unintended consequences identified; 3d. Data collection strategy can be implemented)

<u>Rationale</u>:

- Data for these eight PRO-PMs are collected via a survey that can be administered via mail, telephone, or mixed. Currently the responses of these surveys are not entered by the caregiver directly into an electronic system. The Hospice CAHPS® survey is a survey that is fielded to the caregiver following the death of the hospice patient, and thus, the data elements are not routinely generated and used during care delivery. The response rate for the survey is low, although it is comparable to other CAHPS® surveys.
- The Standing Committee had questions about number of questions on the survey, the methods of completion, and how providers could communicate about the survey—all targeted towards survey

#2651 CAHPS® Hospice Survey (experience with care)

feasibility and increasing survey completion rates. The developer noted that they are working on reducing the number of questions on the survey. The Standing Committee wondered if an option to complete the survey electronically would increase responses. The developer responded that they are working on testing electronic response across all CAHPS® surveys.

- Some Standing Committee members noted that rural areas may not have the same access to broadband internet as other areas and that could be a barrier to online survey completion.
- The Standing Committee had internal discussion about whether online surveys would be a barrier to completion in the older population targeted by the survey. Some felt this group would be less open to technology, and some noted high smart phone usage by this population.
- Some Standing Committee members mentioned there is a belief in the provider community that hospices are not allowed to tell caregivers that they might receive a survey, making survey arrival a (sometimes unwelcome) surprise. The developer clarified that providers could tell caregivers they may receive a survey, but they must inform all caregivers and not just a subset. Providers are not allowed to make any statements about how a caregiver would rate them on the survey.
- The Standing Committee was satisfied the measure met the feasibility criterion.

4. U nd Usability

(4a. Use; 4a1. Accountability and transparency; 4a2. Feedback on the measure by those being measured and others; 4b. Usability; 4b1. Improvement; 4b2. The benefits to patients outweigh evidence of unintended negative consequences to patients)

4a. Use: **Pass-18; No Pass-0** 4b. Usability*:* **H-6; M-12; L-0; I-0**

Rationale:

- The Standing Committee noted the measure is in use in the Hospice Quality Reporting Program and that the results are available on Care Compare. Standing Committee members shared that their organizations carefully reviewed results on this measure and actively worked to improve care to improve measure performance.
- Standing Committee members also reported using the results on Care Compare to find hospice care both for patients and family members. They stated that they found the results of this measure personally useful.
- Overall, the Standing Committee had a positive discussion around the use and usability criteria and was satisfied the measure met both criteria.

5. Related and Competing Measures

- This measure is related to NQF #1623 *Bereaved Family Survey*.
    - The result of the measure is a single score that indicates the family's perceptions of the quality of care that veterans received from the Veterans Affairs (VA) during the last month of life; aspects of care included in the measure are communication, emotional and spiritual support, pain management, and personal care needs.
- The Standing Committee engaged in a brief discussion of #1623 and #2651 as related measures. It felt there was a clear difference between the two measures and stated they are different measures with different populations. The Standing Committee felt the differences between the VA and other health systems justified different measures. Standing Committee members did identify areas, such as questions around supports where the content of the questions could be more aligned, stating there is strong evidence around best-practices in these areas.

6. Standing Committee Recommendation for Endorsement: Y-18; N-0

7. Public and Member Comment

- NQF received one comment that addressed the following:
    - The commenter recommended improving specificity in the questionnaire with respect to person-centered care.
    - The commenter also suggested using a different term than communication to capture the dialogue around what matters most in hospice care and to capture whether the team was able to compassionately act on behalf of patients.

#2651 CAHPS® Hospice Survey (experience with care)

    - The commenter noted that the measures should address the complexity of person-centered care for older adults with multiple chronic conditions and emphasized the need to develop appropriate patient-reported outcome measures.
- The developer replied to the comment saying that they are drafting and field testing a revised version of the CAHPS® Hospice Survey. The developer also mentioned that the team will consider American Geriatrics Society (AGS)'s comment about communication by working with a Technical Expert Panel, conducting inpatient interviews, and developing survey items that assess the degree to which the team was able to communicate about what matters most to the patient. The Standing Committee supported and accepted the developer's response to the comment submitted.

8. Consensus Standards Approval Committee (CSAC): Vote to Uphold the Standing Committee's Recommendation (November 17, 2020): Yes-10; No-0

CSAC Decision: Approved for Endorsement

9. Appeals

- No appeals were received.

Appendix B: Geriatrics and Palliative Care Portfolio—Use in Federal Programs

NQF #	Title	Federal Programs: Finalized or Implemented as of February 8, 2021
0167	Improvement in Ambulation and Locomotion	None
0174	Improvement in Bathing	None
0175	Improvement in Bed Transferring	None
0176	Improvement in Management of Oral Medications	Home Health Quality Reporting (Implemented)
0177	Improvement in pain interfering with activity	Home Health Quality Reporting (Implemented)
0209	Comfortable Dying: Pain Brought to a Comfortable Level Within 48 Hours of Initial Assessment	Merit-Based Incentive Payment System (MIPS) Program (Implemented)
0383	Oncology: Plan of Care for Pain – Medical Oncology and Radiation Oncology (paired with #0384)	Prospective Payment System-Exempt Cancer Hospital Quality Reporting (Implemented) Merit-Based Incentive Payment System (MIPS) Program (Implemented)
0384	Oncology: Medical and Radiation - Pain Intensity Quantified (paired with #0383)	Merit-Based Incentive Payment System (MIPS) Program (Implemented)
0420	Pain Assessment and Follow-Up	None
1617	Patients Treated with an Opioid who are Given a Bowel Regimen	Hospice Quality Reporting (Implemented)
1628	Patients with Advanced Cancer Screened for Pain at Outpatient Visits	None
1634	Hospice and Palliative Care — Pain Screening	Hospice Quality Reporting (Implemented)
1637	Hospice and Palliative Care — Pain Assessment	Hospice Quality Reporting (Implemented)
1638	Hospice and Palliative Care — Dyspnea Treatment	Hospice Quality Reporting (Implemented)
1639	Hospice and Palliative Care — Dyspnea Screening	Hospice Quality Reporting (Implemented)
1647	Beliefs and Values - 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	Hospice Quality Reporting (Implemented)

NQF #	Title	Federal Programs: Finalized or Implemented as of February 8, 2021
0326	Advance Care Plan	Merit-Based Incentive Payment System (MIPS) Program (Implemented)
1626	Patients Admitted to ICU who Have Care Preferences Documented	None
1641	Hospice and Palliative Care – Treatment Preferences	Hospice Quality Reporting (Implemented)
0210	Proportion receiving chemotherapy in the last 14 days of life	Merit-Based Incentive Payment System (MIPS) Program (Implemented) Prospective Payment System – Exempt Cancer Hospital Quality Reporting: (Implemented)
0213	Proportion admitted to the ICU in the last 30 days of life	Merit-Based Incentive Payment System (MIPS) Program (Implemented) Care Compare (Finalized) Prospective Payment System – Exempt Cancer Hospital Quality Reporting: (Implemented)
0215	Proportion not admitted to hospice	Prospective Payment System – Exempt Cancer Hospital Quality Reporting: (Implemented)
0216	Proportion admitted to hospice for less than 3 days	Merit-Based Incentive Payment System (MIPS) Program (Implemented) Prospective Payment System – Exempt Cancer Hospital Quality Reporting: (Implemented)
1623	Bereaved Family Survey	None
1625	Hospitalized Patients Who Die an Expected Death with an ICD that Has Been Deactivated	None
2651	CAHPS® Hospice Survey (Experience with Care): 8 PRO-PMs: (Hospice Team Communication; Getting Timely Care; Getting Emotional and Religious Support; Getting Hospice Training; Rating of the Hospice Care; Willingness to Recommend the Hospice; Treating Family Member with Respect; Getting Help for Symptoms)	Hospice Quality Reporting (Implemented)
3235	Hospice and Palliative Care Composite Process Measure—Comprehensive Assessment at Admission	Hospice Quality Reporting (Implemented)

Appendix C: Geriatrics and Palliative Care Standing Committee and NQF Staff

STANDING COMMITTEE

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Appendix D: Measure Specifications

	2651 CAHPS® Hospice Survey (experience with care)
Steward	Centers for Medicare & Medicaid Services
Description	The measures submitted here are derived from the CAHPS® Hospice Survey, which is a 47-item standardized questionnaire and data collection methodology. The survey is intended to measure the care experiences of hospice patients and their primary caregivers. Respondents to the survey are the primary informal caregivers of patients who died under hospice care. These are typically family members but can be friends. The hospice identifies the primary informal caregiver from their administrative records. Data collection for sampled decedents/caregivers is initiated two months following the month of the decedent's death. The publicly reported measures described here include the following six multi-item measures. • Hospice Team Communication • Getting Timely Care • Treating Family Member with Respect • Getting Emotional and Religious Support • Getting Help for Symptoms • Getting Hospice Training In addition, there are two global rating items that are publicly-reported measures. • Rating of the hospice care • Willingness to recommend the hospice Below we list each multi-item measure and its constituent items, along with the two global rating items. Then we briefly provide some general background information about CAHPS surveys. List of CAHPS Hospice Survey Measures Multi-Item Measures Hospice Team Communication (Composed of 6 items) + 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? + 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? Getting Timely Care (Composed of 2 items) + 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?

	2651 CAHPS® Hospice Survey (experience with care)
	Treating Family Member with Respect (Composed of 2 items) + 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 (Composed of 3 items) + 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? + 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? Getting Help for Symptoms (Composed of 4 items) + 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 receive the help he or she needed from the hospice team for feelings of anxiety or sadness? Getting Hospice Care Training (Composed of 5 items) + Did the hospice team give you enough training 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? + Side effects of pain medicine include things like sleepiness. Did any member of the hospice team discuss side effects of pain medicine with your or your family member? Global Rating Measures: In addition to the multi-item measures, there are two “global” ratings measures. These single-item measures provide families and patients looking for care with overall evaluations of the care provided by the hospice. The items are rating of hospice care and willingness to recommend the hospice. + Rating of Hospice Care: 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? + Willingness to Recommend Hospice: Would you recommend this hospice to your friends and family? The CAHPS Hospice Survey is part of the CAHPS family of experience of care surveys. English and other translations of the survey are available at http://www.hospicecahpssurvey.org/en/survey-instruments/ . CMS initiated national implementation of the CAHPS Hospice Survey in 2015. Hospices meeting CMS eligibility criteria were required to administer the survey for a “dry run” for at least one

	2651 CAHPS® Hospice Survey (experience with care)
	month of sample from the first quarter of 2015. Beginning with the second quarter of 2015, hospices are required to participate on an ongoing monthly basis in order to receive their full Annual Payment Update from CMS. Information regarding survey content and national implementation requirements, including the latest versions of the survey instrument and standardized protocols for data collection and submission, are available at: http://www.hospicecahpssurvey.org/. Public reporting of the survey-based measures on Hospice Compare started in February 2018 (www.medicare.gov Choose find hospice care) A list of the CAHPS Hospice Survey measures, including the components of the multi-item measures can be found in Appendix A
Type	Outcome: PRO-PM
Data Source	Instrument-Based Data CAHPS Hospice Survey; please see S.16 for information regarding modes of data collection. The survey instrument is available in English, Spanish, Chinese, Russian, Portuguese, Vietnamese, Polish and Korean.
Level	Facility
Setting	Other
Numerator Statement	CMS calculates CAHPS Hospice Survey measure scores using top-, middle- and bottom- box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response(s). The bottom box score refers to the percentage of caregiver respondents that give the least positive response(s). The middle box is the proportion remaining after the top and bottom boxes have been calculated; see below for details. Details regarding the definition of most and least positive response(s) are noted in Section S.5 below.
Numerator Details	For each survey item, the top and bottom box numerators are the number of respondents who selected the most and least positive response category(ies), respectively, as follows: For items using a “Never/Sometimes/Usually/Always” response scale, the top box numerator is the number of respondents who answer “Always” and the bottom box numerator is the number of respondents who answer “Never” or “Sometimes.” The one exception to this guidance is for the Q10 “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?” For this item, the top box numerator is the number of respondents who answer “Never” and the bottom box numerator is the number of respondents who answer “Always” or “Usually.” For items using a “Yes, definitely/Yes, somewhat/No” response scale, the top box numerator is the number of respondents who answer “Yes, definitely” and the bottom box numerator is the number of respondents who answer “No.” For items using a “Too Little/Right Amount/Too Much” response scale, the top box numerator is the number of respondents who answer “Right Amount” and the bottom box numerator is the number of respondents who answer “Too little” or “Too much.” (There is no middle box for items using this response scale.) The top box numerator for the Rating of Hospice item is the number of respondents who answer 9 or 10 for the item (on a scale of 0 to 10, where 10 is the “Best Hospice Care Possible”); the bottom box numerator is the number of respondents who answer 0 to 6. The top box numerator for the Willingness to Recommend item is the number of respondents who answer “Definitely Yes” (on a scale of “Definitely No/Probably No/Probably Yes/Definitely Yes”); the bottom box numerator is the number of respondents who answer “Probably No” or “Definitely No.” Calculation of hospice-level multi-item measures 0. Score each item using top- box method, possible values of 0 or 100 1. Calculate mode- adjusted scores for each item for each respondent

	2651 CAHPS® Hospice Survey (experience with care)
	2. Calculate case-mix adjusted scores for each item for each hospice 3. Take the unweighted means of the mode- and case-mix-adjusted hospice-level items to form multi-item measures Here is an example of calculations for the measure "Getting Timely Care." 0. Score each item using top box method, possible values of 0 or 100 Both items in "Getting Care Quickly" have four response options: Never, Sometimes, Usually, Always. Recode each item as 100 for "Always" and 0 for "Never", "Sometimes", or "Usually". Item #1. 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? Item #2. How often did you get the help you needed from the hospice team during evenings, weekends, or holidays? 1. Calculate mode-adjusted scores for each item for each respondent 2. Calculate case-mix adjusted scores for each item for each hospice Each item is case mix adjusted separately; this step produces case-mix adjusted item-level scores for each hospice. 3. Take the unweighted means of the case-mix adjusted hospice-level items to form multi-item measures. If the case-mix adjusted scores for a hospice are 95 for item #1 and 90 for item #2, then the hospice-level 'Getting Timely Care' would be calculated as (Item1 + Item2) / 2 = (95 + 90) / 2 = 92.5.
Denominator Statement	CAHPS® Hospice Survey measure scores are calculated only for hospices that had at least 30 completed questionnaires over the most recent eight quarters of data collection. The target population for the survey are the adult primary caregivers of hospice decedents. Respondent eligibility and exclusions are defined in detail in the sections that follow. A survey is defined as completed when at least 50 percent of the questions applicable to all decedents/caregivers are answered (Questions 1 – 4, 6 – 13, 15, 17, 21, 24, 26, 28, 30 – 32, and 35 – 47). The survey uses screener questions to identify respondents eligible to respond to subsequent items. Therefore, denominators vary by survey item (and corresponding multi-item measures, if applicable) according to the eligibility of respondents for each item. In addition, for the Getting Hospice Care Training measure, scores are calculated only among those respondents who indicate that their family member received hospice care at home or in an assisted living facility.
Denominator Details	For each item in a multi-item measure, as well as for the ratings measures, the top box denominator is the number of respondents per hospice who answered the item. For each multi-item measure score, the denominator is the number of respondents who answer at least one item within the multi-item measure. Multi-item measure scores are the average proportion of respondents that gave responses in the most positive category across the items in the multi-item measure (as discussed in S.6). Survey population: Primary caregivers of patients who died while receiving care from a given hospice in a given month. Denominator for Multi-Item Measures: The number of respondents who answer at least one item within the multi-item measure. Denominator for Rating Measures: The number of respondents who answered the item.
Exclusions	The eight measures included here are calculated only for hospices that have at least 30 completed surveys over eight quarters of data collection.

	2651 CAHPS® Hospice Survey (experience with care)
	The exclusions noted in here are those who are ineligible to participate in the survey. The one exception is caregivers who report on the survey that they "never" oversaw or took part in the decedent's care; these respondents are instructed to complete the "About You" and "About Your Family Member" sections of the survey only. Cases are excluded from the survey target population if: • The hospice patient is still alive • The decedent's age at death was less than 18 • The decedent died within 48 hours of his/her last admission to hospice care • The decedent had no caregiver of record • The decedent had a caregiver of record, but the caregiver does not have a U.S. or U.S. Territory home address • The decedent had no caregiver other than a nonfamilial legal guardian • The decedent or caregiver requested that they not be contacted (i.e., by signing a no publicity request while under the care of hospice or otherwise directly requesting not to be contacted) • The caregiver is institutionalized, has mental/physical incapacity, has a language barrier, or is deceased • The caregiver reports on the survey that he or she "never" oversaw or took part in decedent's hospice care
Exclusion details	Please see S.10.The CAHPS Hospice Survey Quality Assurance Guidelines (available at: http://www.hospicecahpssurvey.org/en/quality-assurance-guidelines/) contain detailed information regarding how to code decedent/caregiver cases, and how to code appropriately and inappropriately skipped items, as well as items with multiple responses.
Risk Adjustment	Statistical risk model
Stratification	CAHPS Hospice Survey measure scores are used for reporting at the hospice-level (i.e., not stratified by region or other characteristics).
Type Score	Rate/proportion better quality = higher score
Algorithm	Top Box Score Calculation: 1) Identify target respondent population (i.e., primary caregivers of hospice patients who died while receiving hospice care from a given hospice in a given month) 2) Identify any exclusions from the respondent population (as described above in S.10) 3) Score each item using top box method, possible values of 0 or 100 4) Calculate mode adjusted top box scores for each item. 5) Calculate case-mix adjusted top box scores for each item for each hospice; case-mix adjustment is a linear regression based approach that adjusts for all variables listed in S.14. Specifically, a regression model predicting item scores is fit using the case-mix adjustor variables and fixed effects for hospices. Adjusted hospice means are then calculated (e.g., using LSMEANS in SAS). 6) Top-box scores are averaged across the items within each multi-item measure, weighting each item equally. If data are missing for a respondent for an item(s) within a multi-item measure, the respondent's answers to other items within the measure are still used in the calculation of multi-item measure scores. (Please see S.22 below for more details). 132021| 141592| 108097
Copyright / Disclaimer	This questionnaire is not copyrighted. However, CAHPS is a copyright of the Agency for Healthcare Research and Quality (AHRQ)

Appendix E: Related and Competing Measures

Comparison of NQF 1623 and NQF 2651

1623: Bereaved Family Survey
2651: CAHPS® Hospice Survey (experience with care)

Steward

1623: Bereaved Family Survey

Department of Veterans Affairs / Hospice and Palliative Care

2651: CAHPS® Hospice Survey (experience with care)

Centers for Medicare & Medicaid Services

Description

1623: Bereaved Family Survey

This measure calculates the proportion of Veteran decedent's family members who rate overall satisfaction with the Veteran decedent's end-of-life care in an inpatient setting as "Excellent" versus "Very good", "good", "fair", or "poor".

2651: CAHPS® Hospice Survey (experience with care)

The measures submitted here are derived from the CAHPS® Hospice Survey, which is a 47-item standardized questionnaire and data collection methodology. The survey is intended to measure the care experiences of hospice patients and their primary caregivers. Respondents to the survey are the primary informal caregivers of patients who died under hospice care. These are typically family members but can be friends. The hospice identifies the primary informal caregiver from their administrative records. Data collection for sampled decedents/caregivers is initiated two months following the month of the decedent’s death.

The publicly reported measures described here include the following six multi-item measures.

- Hospice Team Communication
- Getting Timely Care
- Treating Family Member with Respect
- Getting Emotional and Religious Support
- Getting Help for Symptoms
- Getting Hospice Training

In addition, there are two global rating items that are publicly-reported measures.

- Rating of the hospice care
- Willingness to recommend the hospice

Below we list each multi-item measure and its constituent items, along with the two global rating items. Then we briefly provide some general background information about CAHPS surveys.

List of CAHPS Hospice Survey Measures

Multi-Item Measures

Hospice Team Communication (Composed of 6 items)

+ 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?

+ 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?

Getting Timely Care (Composed of 2 items)

+ 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 (Composed of 2 items)

+ 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 (Composed of 3 items)

+ 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?

+ 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?

Getting Help for Symptoms (Composed of 4 items)

+ 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 receive the help he or she needed from the hospice team for feelings of anxiety or sadness?

Getting Hospice Care Training (Composed of 5 items)

+ Did the hospice team give you enough training 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?

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

Global Rating Measures:

In addition to the multi-item measures, there are two “global” ratings measures. These single-item measures provide families and patients looking for care with overall evaluations of the care provided by the hospice. The items are rating of hospice care and willingness to recommend the hospice.

+ Rating of Hospice Care: 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?

+ Willingness to Recommend Hospice: Would you recommend this hospice to your friends and family?

The CAHPS Hospice Survey is part of the CAHPS family of experience of care surveys. English and other translations of the survey are available at http://www.hospicecahpssurvey.org/en/survey-instruments/ . CMS initiated national implementation of the CAHPS Hospice Survey in 2015. Hospices meeting CMS eligibility criteria were required to administer the survey for a “dry run” for at least one month of sample from the first quarter of 2015. Beginning with the second quarter of 2015, hospices are required to participate on an ongoing monthly basis in order to receive their full Annual Payment Update from CMS. Information regarding survey content and national implementation requirements, including the latest versions of the survey instrument and standardized protocols for data collection and submission, are available at: http://www.hospicecahpssurvey.org/. Public reporting of the survey-based measures on Hospice Compare started in February 2018 (www.medicare.gov Choose find hospice care)

A list of the CAHPS Hospice Survey measures, including the components of the multi-item measures can be found in Appendix A

Type

1623: Bereaved Family Survey

Outcome: PRO-PM

2651: CAHPS® Hospice Survey (experience with care)

Outcome: PRO-PM

Data Source

1623: Bereaved Family Survey

Instrument-Based Data For 2a1.25 - Family reported data/survey.

For 2a1.26 - Bereaved Family Survey

Available in attached appendix at A.1 No data dictionary

2651: CAHPS® Hospice Survey (experience with care)

Instrument-Based Data CAHPS Hospice Survey; please see S.16 for information regarding modes of data collection. The survey instrument is available in English, Spanish, Chinese, Russian, Portuguese, Vietnamese, Polish and Korean.

Available at measure-specific web page URL identified in S.1 No data dictionary

Level

1623: Bereaved Family Survey

Facility, Other

2651: CAHPS® Hospice Survey (experience with care)

Facility

Setting

1623: Bereaved Family Survey

Inpatient/Hospital, Post-Acute Care

2651: CAHPS® Hospice Survey (experience with care)

Other

Numerator Statement

1623: Bereaved Family Survey

The numerator is comprised of completed surveys (at least 12 of 17 structured items completed), where the global item question has an optimal response. The global item question asks "Overall, how would you rate the care that [Veteran] received in the last month of life" and the possible answer choices are: Excellent, Very good, Good, Fair, or Poor. The optimal response is Excellent.

2651: CAHPS® Hospice Survey (experience with care)

CMS calculates CAHPS Hospice Survey measure scores using top-, middle- and bottom- box scoring. The top-box score refers to the percentage of caregiver respondents that give the most positive response(s). The bottom box score refers to the percentage of caregiver respondents that give the least positive response(s). The middle box is the proportion remaining after the top and bottom boxes have been calculated; see below for details. Details regarding the definition of most and least positive response(s) are noted in Section S.5 below.

Numerator Details

1623: Bereaved Family Survey

Included are those patients included in the denominator with completed surveys (at least 12 of 17 structured items completed) that receive an optimal response on the global item question.

2651: CAHPS® Hospice Survey (experience with care)

For each survey item, the top and bottom box numerators are the number of respondents who selected the most and least positive response category(ies), respectively, as follows:

For items using a “Never/Sometimes/Usually/Always” response scale, the top box numerator is the number of respondents who answer “Always” and the bottom box numerator is the number of respondents who answer “Never” or “Sometimes.” The one exception to this guidance is for the Q10 “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?” For this item, the top box numerator is the number of respondents who answer “Never” and the bottom box numerator is the number of respondents who answer “Always” or “Usually.”

For items using a “Yes, definitely/Yes, somewhat/No” response scale, the top box numerator is the number of respondents who answer “Yes, definitely” and the bottom box numerator is the number of respondents who answer “No.”

For items using a “Too Little/Right Amount/Too Much” response scale, the top box numerator is the number of respondents who answer “Right Amount” and the bottom box numerator is the number of respondents who answer “Too little” or “Too much.” (There is no middle box for items using this response scale.)

The top box numerator for the Rating of Hospice item is the number of respondents who answer 9 or 10 for the item (on a scale of 0 to 10, where 10 is the "Best Hospice Care Possible"); the bottom box numerator is the number of respondents who answer 0 to 6.

The top box numerator for the Willingness to Recommend item is the number of respondents who answer "Definitely Yes" (on a scale of "Definitely No/Probably No/Probably Yes/Definitely Yes"); the bottom box numerator is the number of respondents who answer "Probably No" or "Definitely No."

Calculation of hospice-level multi-item measures

0. Score each item using top- box method, possible values of 0 or 100

1. Calculate mode- adjusted scores for each item for each respondent

2. Calculate case-mix adjusted scores for each item for each hospice

3. Take the unweighted means of the mode- and case-mix-adjusted hospice-level items to form multi-item measures

Here is an example of calculations for the measure "Getting Timely Care."

0. Score each item using top box method, possible values of 0 or 100

Both items in "Getting Care Quickly" have four response options: Never, Sometimes, Usually, Always. Recode each item as 100 for "Always" and 0 for "Never", "Sometimes", or "Usually".

Item #1. 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?

Item #2. How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?

1. Calculate mode-adjusted scores for each item for each respondent

2. Calculate case-mix adjusted scores for each item for each hospice

Each item is case mix adjusted separately; this step produces case-mix adjusted item-level scores for each hospice.

3. Take the unweighted means of the case-mix adjusted hospice-level items to form multi-item measures.

If the case-mix adjusted scores for a hospice are 95 for item #1 and 90 for item #2, then the hospice-level 'Getting Timely Care' would be calculated as (Item1 + Item2) / 2 = (95 + 90) / 2 = 92.5.

Denominator Statement

1623: Bereaved Family Survey

The denominator consists of all inpatient deaths for which a survey was completed (at least 12 of 17 structured items completed), excluding: 1) deaths within 24 hours of admission (unless the Veteran had a previous hospitalization in the last month of life); 2) deaths that occur in the Emergency Department (unless the Veteran had a prior hospitalization of at least 24 hours in the last 31 days of life); Additional exclusion criteria include: 1) Veterans for whom a family member knowledgeable about their care cannot be identified (determined by the family member's report); or contacted (no current contacts listed or no valid addresses on file); 2) absence of a working telephone available to the family member.

2651: CAHPS® Hospice Survey (experience with care)

CAHPS® Hospice Survey measure scores are calculated only for hospices that had at least 30 completed questionnaires over the most recent eight quarters of data collection.

The target population for the survey are the adult primary caregivers of hospice decedents. Respondent eligibility and exclusions are defined in detail in the sections that follow. A survey is defined as completed when at least 50 percent of the questions applicable to all decedents/caregivers are answered (Questions 1 – 4, 6 – 13, 15, 17, 21, 24, 26, 28, 30 – 32, and 35 – 47). The survey uses screener questions to identify respondents eligible to respond to subsequent items. Therefore, denominators vary by survey item (and corresponding multi-item measures, if applicable) according to the eligibility of respondents for each item. In addition, for the Getting Hospice Care Training measure, scores are calculated only among those respondents who indicate that their family member received hospice care at home or in an assisted living facility.

Denominator Details

1623: Bereaved Family Survey

The purpose of this measure is to assess families' perceptions of the quality of care that Veterans received from the VA in the last month of life. The BFS consists of 19 items (17 structured and 2 open-ended). The BFS items were selected from a longer survey that was developed and validated with the support of a VA HSR&D Merit Award and have been approved for use by the Office of Management and Budget.

Seventeen items in the survey have predefined response options and ask family members to rate aspects of the care that the Veteran received from the VA in the last month of life. These items cover areas of care such as communication, emotional and spiritual support. Two additional items are open-ended and give family members the opportunity to provide comments regarding the care the patient received.

A growing body of research has underscored the degree to which end-of-life care in the United States needs to be improved. The challenges of end-of-life care are particularly significant in the U.S. Department of Veterans Affairs Health Care system because the VA provides care for an increasingly older population with multiple comorbid conditions. In FY2000, approximately 104,000 enrolled Veterans died in the U.S., and approximately 27,200 Veterans died in VA facilities. At least 30% of the Veterans are over age 65 now, and 46% will be over 65 by 2030. Therefore, it is clear that the number of deaths in VA facilities will increase substantially as the World War II and Korean War Veterans age. These demographic trends mean that, like other healthcare systems, the VA will face substantial challenges of providing care to Veterans near the end-of-life.

The VA has addressed this challenge aggressively in the last 5 year, however the VA has not yet developed and implemented measures of the quality of end-of-life care it provides to Veterans. There are at least 3 reasons why adoption of a quality measurement tool is essential. First, it would make it possible to define and compare the quality of end-of-life care at each VA facility and to identify opportunities for improvement. Second, facilities and VISNs (geographic service divisions within the VA system) would be able to monitor the effectiveness of efforts to improve care locally and nationally, and would enable monitoring of the impact of the Comprehensive End of Life Care Initiative, ensuring that expenditures are producing improvements in care. Third, it will help the VA to recognize those facilities that provide outstanding end-of-life care, so that successful processes and structures of care can be identified and disseminated throughout the VA.

The BFS's 17 close-ended items ask family members to rate aspects of the care that the Veteran received from the VA in the last month of life. These items cover areas of care such as communication, emotional and spiritual support, pain management and personal care needs. Two additional items (not used in scoring) are open-ended and give family members the opportunity to provide comments regarding the care the patient received. The BFS has undergone extensive development and has been pilot-tested for all inpatient deaths in Q4FY2008 in seven VISNs (1,2,4,5,8,11, and 22). As of October 1, 2009, Q1FY2010, all inpatient deaths in all VISNs were included in the project.

The indicator denominator is comprised of the number of Veterans who die in an inpatient VA facility (intensive care, acute care, hospice unit, nursing home care or community living center) for whom a survey is completed. Completed surveys are defined as those with at least 12 of the 17 structured items completed.

2651: CAHPS® Hospice Survey (experience with care)

For each item in a multi-item measure, as well as for the ratings measures, the top box denominator is the number of respondents per hospice who answered the item. For each multi-item measure score, the denominator is the number of respondents who answer at least one item within the multi-item measure. Multi-item measure scores are the average proportion of respondents that gave responses in the most positive category across the items in the multi-item measure (as discussed in S.6).

Survey population: Primary caregivers of patients who died while receiving care from a given hospice in a given month.

Denominator for Multi-Item Measures: The number of respondents who answer at least one item within the multi-item measure.

Denominator for Rating Measures: The number of respondents who answered the item.

Exclusions

1623: Bereaved Family Survey

- Veterans for whom a family member knowledgeable about their care cannot be identified (determined by family member's report)

- Absence of a current address and/or working telephone number for a family member or emergency contact.

- Deaths within 24 hours of admission without a prior hospitalization of last least 24 hours in the last 31 days of life.

- Deaths that occur in the operating room during an outpatient procedure.

- Deaths due to a suicide or accident

- Surveys in which less than 12 items were answered.

-

2651: CAHPS® Hospice Survey (experience with care)

The eight measures included here are calculated only for hospices that have at least 30 completed surveys over eight quarters of data collection.

The exclusions noted in here are those who are ineligible to participate in the survey. The one exception is caregivers who report on the survey that they “never” oversaw or took part in the decedent’s care; these respondents are instructed to complete the “About You” and “About Your Family Member” sections of the survey only.

Cases are excluded from the survey target population if:

- The hospice patient is still alive
- The decedent’s age at death was less than 18
- The decedent died within 48 hours of his/her last admission to hospice care
- The decedent had no caregiver of record
- The decedent had a caregiver of record, but the caregiver does not have a U.S. or U.S. Territory home address
- The decedent had no caregiver other than a nonfamilial legal guardian
- The decedent or caregiver requested that they not be contacted (i.e., by signing a no publicity request while under the care of hospice or otherwise directly requesting not to be contacted)
- The caregiver is institutionalized, has mental/physical incapacity, has a language barrier, or is deceased
- The caregiver reports on the survey that he or she “never” oversaw or took part in decedent’s hospice care

Exclusion Details

1623: Bereaved Family Survey

Name, address, and phone number of patient's family member or emergency contact are required for determining exclusion. In addition, information regarding the patient's admission(s) during the last 31 days of life, and including length of stay are also required to determine exclusion.

2651: CAHPS® Hospice Survey (experience with care)

Please see S.10.The CAHPS Hospice Survey Quality Assurance Guidelines (available at: http://www.hospicecahpssurvey.org/en/quality-assurance-guidelines/) contain detailed information regarding how to code decedent/caregiver cases, and how to code appropriately and inappropriately skipped items, as well as items with multiple responses.

Risk Adjustment

1623: Bereaved Family Survey

Statistical risk model

2651: CAHPS® Hospice Survey (experience with care)

Statistical risk model

Stratification

1623: Bereaved Family Survey

Variables necessary to stratify the measure are VISN, facility, quarter, year, outcome. VISN refers to "Veterans Integrated Service Network" and is a geographic area of the country where a facility is located. Facility is the actual VA medical center or affiliated community living center where the Veteran died. Quarter is the 3 month time period in which the patient died. Year is the VA fiscal year (runs from Oct 1 to Sept 30). Outcome refers to whether or not a survey was completed.

2651: CAHPS® Hospice Survey (experience with care)

CAHPS Hospice Survey measure scores are used for reporting at the hospice-level (i.e., not stratified by region or other characteristics).

Type Score

1623: Bereaved Family Survey

Rate/proportion better quality = higher score

2651: CAHPS® Hospice Survey (experience with care)

Rate/proportion better quality = higher score

Algorithm

1623: Bereaved Family Survey

The purpose of this measure is to assess families' perceptions of the quality of care that Veterans received from the VA in the last month of life. The BFS consists of 19 items (17 structured and 2 open-ended). The BFS items were selected from a longer survey that was developed and validated with the support of a VA HSR&D Merit Award and have been approved for use by the Office of Management and Budget.

Seventeen items in the survey have predefined response options and ask family members to rate aspects of the care that the Veteran received from the VA in the last month of life. These items cover areas of care such as communication, emotional and spiritual support. Two additional items are open-ended and give family members the opportunity to provide comments regarding the care the patient received.

A growing body of research has underscored the degree to which end-of-life care in the United States needs to be improved. The challenges of end-of-life care are particularly significant in the U.S. Department of Veterans Affairs Health Care system because the VA provides care for an increasingly older population with multiple comorbid conditions. In FY2000, approximately 104,000 enrolled Veterans died in the U.S., and approximately 27,200 Veterans died in VA facilities. At least 30% of the Veterans are over age 65 now, and 46% will be over 65 by 2030. Therefore, it is clear that the number of deaths in VA facilities will increase substantially as the World War II and Korean War Veterans age. These demographic trends mean that, like other healthcare systems, the VA will face substantial challenges of providing care to Veterans near the end-of-life.

The VA has addressed this challenge aggressively in the last 5 year, however the VA has not yet developed and implemented measures of the quality of end-of-life care it provides to Veterans. There are at least 3 reasons why adoption of a quality measurement tool is essential. First, it would make it possible to define and compare the quality of end-of-life care at each VA facility and to identify opportunities for improvement. Second, facilities and VISNs (geographic service divisions within the VA system) would be able to monitor the effectiveness of efforts to improve care locally and nationally, and would enable monitoring of the impact of the Comprehensive End of Life Care Initiative, ensuring that expenditures are producing improvements in care. Third, it will help the VA to recognize those facilities that provide outstanding end-of-life care, so that successful processes and structures of care can be identified and disseminated throughout the VA.

The BFS's 17 close-ended items ask family members to rate aspects of the care that the Veteran received from the VA in the last month of life. These items cover areas of care such as communication, emotional and spiritual support, pain management and personal care needs. Two additional items (not used in scoring) are open-ended and give family members the opportunity to provide comments regarding the care the patient received. The BFS has undergone extensive development and has been pilot-tested for all inpatient deaths in Q4FY2008 in seven VISNs (1,2,4,5,8,11, and 22). As of October 1, 2009, Q1FY2010, all inpatient deaths in all VISNs were included in the project.

The 17 structured items of the Bereaved Family Survey are scored as either "1" (optimal response) or "0" (all other answer choices). A score of "1" indicates that the family member perceived that the care they and/or the Veteran received was the best possible care (Excellent). A score of "0" reflects all other possible responses (Very good, Good, Fair, Poor). Items are coded as missing if respondents cannot or refuse to answer the item. Thus, the score for each item can be expressed as a fraction corresponding to the number of families who reported that the Veteran received optimal care (numerator), divided by the number of valid, non-missing responses for that item (denominator). Similarly, the score for the 17-item survey is calculated based on the global question item (Overall, how would you rate the care received in the last month of life? - Excellent, Very Good, Good, Fair, Poor). The global item is scored as the # of optimal responses/# of valid, non-missing responses for all completed surveys (12 of 17 structured items answered). This scoring system produces a facility- or VISN-level score that reflects the proportion of Veterans who received the best possible care overall (BFS score) and in specific areas corresponding to BFS items (e.g., pain management, communication, personal care, etc.).

We then add nonresponse and patient case mix weights to the model. All adjusted scores are reported. The purpose of this measure is to assess families' perceptions of the quality of care that Veterans received from the VA in the last month of life. The BFS consists of 19 items (17 structured and 2 open-ended). The BFS items were selected from a longer survey that was developed and validated with the support of a VA HSR&D Merit Award and have been approved for use by the Office of Management and Budget.

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We then add nonresponse and patient case mix weights to the model. All adjusted scores are reported.

2651: CAHPS® Hospice Survey (experience with care)

Top Box Score Calculation:

1) Identify target respondent population (i.e., primary caregivers of hospice patients who died while receiving hospice care from a given hospice in a given month)

2) Identify any exclusions from the respondent population (as described above in S.10)

3) Score each item using top box method, possible values of 0 or 100

4) Calculate mode adjusted top box scores for each item.

5) Calculate case-mix adjusted top box scores for each item for each hospice; case-mix adjustment is a linear regression based approach that adjusts for all variables listed in S.14. Specifically, a regression model predicting item scores is fit using the case-mix adjustor variables and fixed effects for hospices. Adjusted hospice means are then calculated (e.g., using LSMEANS in SAS).

6) Top-box scores are averaged across the items within each multi-item measure, weighting each item equally. If data are missing for a respondent for an item(s) within a multi-item measure, the respondent’s answers to other items within the measure are still used in the calculation of multi-item measure scores. (Please see S.22 below for more details). Top Box Score Calculation:

1) Identify target respondent population (i.e., primary caregivers of hospice patients who died while receiving hospice care from a given hospice in a given month)

2) Identify any exclusions from the respondent population (as described above in S.10)

3) Score each item using top box method, possible values of 0 or 100

4) Calculate mode adjusted top box scores for each item.

5) Calculate case-mix adjusted top box scores for each item for each hospice; case-mix adjustment is a linear regression based approach that adjusts for all variables listed in S.14. Specifically, a regression model predicting item scores is fit using the case-mix adjustor variables and fixed effects for hospices. Adjusted hospice means are then calculated (e.g., using LSMEANS in SAS).

6) Top-box scores are averaged across the items within each multi-item measure, weighting each item equally. If data are missing for a respondent for an item(s) within a multi-item measure, the respondent's answers to other items within the measure are still used in the calculation of multi-item measure scores. (Please see S.22 below for more details).

Submission items

1623: Bereaved Family Survey

5.1 Identified measures: 2651: CAHPS® Hospice Survey (experience with care)

5a.1 Are specs completely harmonized? No

5a.2 If not completely harmonized, identify difference, rationale, impact: Survey items different as well as coding of items, Target group is also different, We are specifically looking at inpatient Veteran deaths, regardless of hospice use. Currently, the BFS is the only tool assessing end of life care in a VA inpatient setting. We believe that assessing all deaths, not just hospice deaths, is critical to the VA mission of improving care for all Veterans regardless of choice of level of care at death. We do see any negative impact to interpretability or burden of data collection.

5b.1 If competing, why superior or rationale for additive value: NQF 2651 CAHPS Hospice Survey

Although the Bereaved Family Survey is in many ways similar to the CAHPS Hospice Survey, it provides information on a specific population (Veterans) and measures the quality of care provided a single health care system. Unlike the CAHPS-Hospice, the BFS provides a coherent measurement strategy that allows comparisons across systems of care and sites of death in a single health care system. This measure assesses the quality of care of the largest unified health care system in the United States and cares for more than 5 million patients annually. Because it is a unified health system, the VA is uniquely situated to make use of the quality data that can be easily and quickly disseminated. The BFS also measures satisfaction of care that are unique to a Veteran population (i.e., survivor and funeral benefits, PTSD). The population of Veterans and families that the VA serves is unique in several key respects: 1) Veterans and their families may face different challenges at the end of life than non-Veterans do. The costs of hospitalization are less likely to be relevant to non-VA populations.

2651: CAHPS® Hospice Survey (experience with care)

5.1 Identified measures: 0208: Family Evaluation of Hospice Care

1623: Bereaved Family Survey

5a.1 Are specs completely harmonized? Yes

5a.2 If not completely harmonized, identify difference, rationale, impact: N/A

5b.1 If competing, why superior or rationale for additive value: 0208 Family Evaluation of Hospice Care.

The Family Evaluation of Hospice Care Survey (FEHC) developed more than 20 years ago, assesses hospice care experiences from the perspective of bereaved family members. The CAHPS Hospice Survey covers similar domains, but includes important methodological improvements in the response task, and is adjusted for case mix and mode. Additionally, more stringent survey administration guidelines are in place to permit public reporting of the survey results and valid comparison across hospice programs. FEHC measures were maintained by the National Hospice and Palliative Care Organization (NHPCO), which operated a voluntary repository that provided hospice programs with national benchmarks for FEHC measures. With the national implementation of the CAHPS Hospice Survey, NHPCO shut down the voluntary repository. NQF endorsement of FEHC measures was removed in January 2018.

1623 Bereaved Family Survey.

The Department of Veterans Affairs Bereaved Family Survey assesses experiences of veterans' health care in the last month of life from the perspective of bereaved family members. Importantly, the Bereaved Family Survey assesses care for those who die in inpatient settings, regardless of whether they have received hospice care; this is distinct from respondents to the CAHPS Hospice Survey, who include informal caregivers of decedents who received hospice care across a range of care settings (including both inpatient and other settings).

Appendix F: Pre-Evaluation Comments

No pre-evaluation comments were received.

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