

Development of the Hospice Experience of Care Survey

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Agenda

- Overview of hospice experience of care survey (HECS) development
 - Survey design principles
 - Defining hospice care quality
 - Literature review
 - Technical Expert Panel and Call for Topic Areas
 - Focus groups
 - Cognitive tests
 - Field test
- Field test survey contents
 - Comparison to the FEHC
- Next steps: onward to national implementation
- Q & A

Objectives

- To describe the development, content, and purpose of the new CMS hospice experience of care survey
- To compare the new survey to existing experience surveys, particularly the Family Evaluation of Hospice Care (FEHC)
- To provide an overview of the survey requirement for FY2015
- To consider the potential implications of the new hospice experience survey on hospices' quality improvement activities

Overview of Survey Design

Survey is designed to produce comparable data on experiences of hospice care to enable objective and meaningful comparisons between hospice care providers, utilizing domains that are important to consumers, and focusing on areas where the informal caregiver is the best or only source of information.

Survey Design Principles (1)

- Must be in keeping with externally validated, quality-of-life-related aspects of hospice care (e.g., NQF preferred practices).
- Capture patient and/or caregiver experience, rather than care processes that may be measured by other sources of data.
- Measure aspects of care experience that patients and/or caregivers deem important.
- Be under the control of the hospice provider.

Survey Design Principles (2)

- Develop survey language that most respondents find easy to understand.
- Be clear about the time frames that we are asking respondents to assess.
- To the extent possible, cover all disease trajectories, recognizing that not all survey items are applicable to all trajectories.
- Use screener questions to identify the denominator of consumers who can report on an experience or provide a rating.

Survey Design Principles (3)

Two types of questions:

Reports of Specific Experiences

- E.g., "While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?"
 - Responses capture frequency using the Never/Always scale whenever possible.

Ratings of Care

- E.g., "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?"
 - Use a 0 to 10 scale rather than adjectival scale whenever possible.

Defining Hospice Care Quality: What is Quality of Medical Care?

Institute of Medicine definition:

"Degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with professional knowledge."

**Defining Hospice Care Quality:
What is so different about end-of-life care?**



While one is dying, life takes on a new shape – values change. Things once ignored become more important.

What is more important to this woman: mammogram rates or being treated by the same provider with compassion?

**Defining Hospice Care Quality:
What is so different about end-of-life care?**

Quality of medical care for...

- 45 y/o AMI with chest pain
 - Presumption to preserve function
 - Evidence base on treatment is 5,319 papers just in the last two years. Of these, 519 are RCTs.
- 79 y/o lung cancer with dyspnea
 - Presumption to preserve function does not necessarily hold
 - Evidence base is 13 articles with only one RCT

**Defining Hospice Care Quality: Patient Focused,
Family Centered Medical Care**

- Provide the desired level of physical comfort and emotional support
- Promote shared decision making
- Treat with respect and dignity
- Attend to the needs of caregivers for information and skills in providing care for the patient, and provide emotional support to the family before and after the patient's death.
- Coordinate care

Defining Hospice Care Quality:
Adaptation of the Key Elements of the National Consensus Project and National Quality Forum's "A National Framework and Preferred Practices for Palliative and Hospice Care Quality"

- Plan of care is based on the **goals, values, and needs of the patient and family**. This is regularly reviewed, shared with the family, and other health care providers. (NQF preferred practice 6,10,33,34,36)
- An **interdisciplinary team** provides services to the patient and family that is available, 24 hours, 7 days a week. Disciplines should include medical, nursing, social work, and spiritual care professionals who hold certification in palliative care (NQF preferred practice 1,2, 21, 22, 23)
- Assessment, plan of care, and treatment are **evidence-based and include the following domains: a) physical symptoms; b) emotional distress; c) grief and bereavement; d) spiritual, religious, and existential concerns** (NQF practices 12-18,20)
- **Care coordination** should occur across the disease trajectory and the health care institutions and providers involved in the care of the patient and family. Palliative care teams should have relationships with one or more institutions to provide high quality continuity care throughout the disease trajectory. **This includes hospice.** (NQF 7,8)
- **Social, practical, and legal aspects** of the patient and family are addressed as part of the social care plan. (NQF preferred practice 19)
- Care is **culturally sensitive** to the spiritual and social values and customs of the patient and family. (NQF preferred practice 24)
- Recognizes and appropriately manages the actively **dying patient**. (NQF preferred practices 26, 27)
- The palliative care team strives for excellence through **quality improvement** and management. (Domain 1 of NQF report)

**Systematic Literature Review:
Overview**

- Identified 87 published articles (after full-text review) that use surveys to measure experiences of end-of-life care
- Abstracted 50 distinct survey instruments
- Coded survey items into 14 content areas
- Abstracted information regarding administration of 12 most common surveys:
 - Identification of proxy respondents
 - Timing of administration
 - Mode of administration

**Systematic Literature Review:
Most Common Survey Content Areas**

Content Area	Frequency (Approximate)
Information & Care Planning	45
Provider Care	35
Symptoms	30
Overall Experience	28
Spiritual/Existential	25
Psychosocial Care	22
Cognitive Support	20
Responsiveness & Timing	18
Other	15
Personal Care	12
Bereavement Support	10
Quality of Death	8
Environment	7
Financial Needs	6

**Systematic Literature Review:
Survey Administration Procedures**

- Proxy respondents:
 - “Family members” or “close relatives” (n=26 surveys)
 - “Caregiver” (n = 17)
 - “Healthcare proxy,” “decision-making surrogate,” “power of attorney,” or “medical contact” (n = 10)
- Timing of administration (following death):
 - Wide range from 3-6 weeks to 372 days; majority (n=21) within 1-6 months
- Survey mode:
 - In-person paper or interview (n = 23)
 - Mail (n = 20)
 - Telephone (n = 19)

**Technical Expert Panel and
Call for Topic Areas**

- Panel of experts on survey research and hospice care quality convened to discuss:
 - Field test survey methods
 - Survey content
- Call for Topic Areas published in Federal Register to elicit suggestions for potential survey items and topics from organizations and stakeholder groups

Qualitative Interviews

- Interviewed primary caregivers of patients who died in hospice in the prior 6 to 12 months
 - Recruited from hospices across the country
 - Interviewees diverse by care setting (home, nursing home, facility/ICU), income (low, high)
- Semi-structured discussion guides tailored to care setting
- Transcripts reviewed by multiple team members to identify common themes

**Qualitative Interviews:
Caregivers Identify What’s Important (I)**

- **Whether hospice explained what kinds of services they could offer the family and patient**
“The other thing I think would be better that I really wasn’t aware of, was everything that hospice provided. Like I didn’t know that hospice provided beds and walkers and wheelchairs.”
- **Information on communication and care responsibilities for patients receiving hospice care in nursing homes**
“The [nursing home] care initially was not good. Actually, across the board it wasn’t good. I was always at the nurses’ station asking questions, talking to the head of nursing, voicing my concerns on the care that my aunt was given.... Then I found out that I could get even more help from hospice. That’s what we were initiating so that I would have another person, or persons, to go up more and have more eyes on her and more care given to her to make sure someone was helping to feed her.”

**Qualitative Interviews:
Caregivers Identify What’s Important (II)**

- **Amount of time spent with the patient**
“Well, just they never seemed to be in a hurry. They didn’t just rush in and rush out.”
- **Dignity and respect provided to patient, and the degree to which the hospice staff seemed to “really care” about the patient and family**
“They’re really good people, people who really cared, who spent the time with him and treated him with respect.”
- **How much privacy was afforded to the patient and family by hospice staff**
- **Caregiver trust of hospice team members**
“Well, if the nurses that came did what they say they were going to do. If they explained what they were going to do to me as well as to their patient. It made a huge difference in the trust that they built up with my husband and me.”

**Qualitative Interviews:
Caregivers Identify What’s Important (III)**

- **Keeping the family informed about the patient’s condition**
“And I liked that they were very proactive on talking to me, as opposed to waiting for me to contact them if I had any questions. There was a lot of interaction that I appreciated.”
- **How well pain was managed & side effects of the pain medication**
“And the one thing I wish they had told me or made sure I understood was how quickly they would put him in coma with the morphine. I had no idea I would not be able to communicate—or that he wouldn’t be able to communicate with us.”
- **Information provided about what to expect while a family member is actively dying**
- **Follow-up care after the patient’s death**

Cognitive Interviews

- Conducted 2 rounds of interviews to cognitively test 3 setting-specific survey versions
- Participants were English- and Spanish-speaking caregivers of patients who died in hospice in the prior 6 to 12 months
 - Recruited from hospices across the country
 - Interviewees diverse by care setting (home, nursing home, facility/ICU), income (low, high)
- Draft surveys revised to reflect interview findings

Cognitive Interviews: Clarifying Concepts and Language

- Refined carrier phrase to identify time frame under assessment
 - “While your family member was in hospice care...”
- Importance of distinguishing between patient and caregiver experiences with hospice
 - E.g., “...how often did hospice team spend enough time with you” vs. “... with your family member”?
- Little involvement in decisions about pain management, but great interest in knowing side effects of pain medicine

Field Test: Sample Selection

- 33 hospice programs purposively recruited to reflect diversity in:
 - Size (patient volume)
 - Chain status
 - Ownership (i.e., government, for-profit, not-for-profit)
 - Geographic region
 - Rural/urban
- Identified primary caregivers of hospice patients from hospice administrative records
 - Sampled all caregivers of decedents in nursing home, inpatient settings, and subset of decedents from home setting

**Field Test:
Inclusion Criteria**

- Patients over the age of 18
- Patients with death at least 48 hours following admission to final setting of hospice care
- Patients for whom a caregiver is listed or available and for whom caregiver contact information is known
- Patients whose primary caregiver is someone other than a non-familial legal guardian
- Patients for whom the primary caregiver has a U.S. or U.S. Territory home address

- **Inclusion criteria may be updated for national implementation**

**Field Test:
Survey Administration**

- Field period of 42 days in November & December 2013
- Primary caregivers surveyed 2 to 3.5 months following death of hospice patient
- Mixed-mode (mail & telephone) methodology
 - Mailed survey + prompt letter one week later
 - Telephone interviews (up to 5 attempts)
- Survey available in English and Spanish

- **Administration procedures may be updated for national implementation**

**Field Test:
Survey Content**

- Core survey questions examine:
 - Access to care
 - Communication
 - Symptom management (pain, dyspnea, constipation, anxiety/sadness)
 - Emotional & spiritual support
 - Overall rating
 - Demographics
- Setting-specific versions assigned according to final setting of care
 - Home (72 questions): special medical equipment, information/training
 - Nursing home (65 questions): coordination between NH and hospice staff
 - Inpatient (67 questions): room environment, enough time with doctor

- **Data analyses currently underway will inform final survey content**
 - Final survey will be approximately 2/3 the length of field test instrument

The Road Ahead:
Preparing for National Implementation



Second Beach, Middletown RI
Only in Rhode Island

What are the difference between the
FEHC and HECS?

- Many questions/answers have been reworded to reflect CAHPS design principles or interview findings
 - Standard response categories
 - Yes definitely; Yes, somewhat; No
 - Never; Sometimes; Usually; Always
 - 0-10 (instead of Excellent/VG/G/F/Poor)
 - Time frame indicated in most questions
 - “While your family member was in hospice care...”
 - Wording changes
 - E.g., “dignity and respect” instead of “respect”

New Questions on the HECS

- Examples of questions new on the HECS:
 - Get help needed during evening, weekends, or holidays?
 - Get help as soon as needed?
 - Hospice team give you and your family enough privacy?
 - Feel that the hospice team really cared about your family member?

Case Study:
Definition of Safety in Hospice

When her daughter leaves the house to run errands, GL is left in the care of a neighbor, who mistakenly gives GL four long-acting morphine tablets for breakthrough pain. GL becomes increasingly somnolent and has a respiratory arrest six hours later. When the error is discovered, the hospice reports GL's death as a serious reportable adverse event.

Based on Casarett, J Palliat Med 2013

Case Study Discussion

- Was this overdose preventable?
 - Why or why not?
- Should it be considered as an adverse event?
- Should the hospice be held accountable for overdoses like these?
- What are other ways to measure medication safety when multiple people are involved in a patient's care?

Problems with Applying Existing Safety Measures

- "Medication errors should be avoidable"
- But:
 - Doesn't recognize that many people are involved in a patient's care
 - Hospice may or may not be responsible

Solutions/principle

- Safety measures for hospice should reflect the degree to which hospice is in control of processes and outcomes.
- Hospice should be held accountable for aspects of care under their control:
 - Some events are hospice’s responsibility (medication prescribing)
 - Other processes (e.g. family education) are under a hospice’s control

Both the FEHC and HECS...

- Developed a series of questions on informing and training the caregiver regarding key processes of care.
 - E.g. from HECS: Did the hospice team give you enough training about if and when to give more pain medicine to your family member?
 - Yes, definitely
 - Yes, somewhat
 - No

**Comparing the FEHC and the HECS:
Change is Good!**

- It will be shorter!
 - Final survey instrument will be substantially shorter than FEHC and field test version of HECS
- Questions that field had concerns about will be DROPPED
 - New survey does not include questions about self-efficacy, psychological state
- Newer content that examines emerging sites of care (NH and IPU)

**Looking Ahead:
National Implementation of the HECS**

- Dry run for at least one month in 1Q2015.

- Starting 2Q2015, hospices will be required to participate on a monthly basis in order to receive the full Annual Payment Update (APU).
 - Participation will impact the FY 2017 APU.
 - Hospices must contract with an approved third party vendor to conduct the survey in accordance with CMS guidelines.

- Further details regarding compliance with the HECS will be included in the FY 2015 rule.

**Looking Ahead:
Making the Transition to the New Survey**

- Personnel knowledgeable about data use agreements, hospice data systems, secure data handling and data transfer
- Development of efficient means of extracting data variables needed for survey sampling
- Identifying the name of the hospice that should be used on the hospice cover letter to maximize the likelihood that caregivers will recognize it.
- Identifying the “primary caregiver” (i.e., respondent who was most meaningfully involved in care)
 - Ensuring the most complete and up-to-date records regarding name, contact information, and relationship between primary caregiver and patient

Questions


