

## Original Article

# Timing of Survey Administration After Hospice Patient Death: Stability of Bereaved Respondents

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## Abstract

**Context.** The Centers for Medicare & Medicaid Services have elected to include a bereaved family member survey in public reporting of hospice quality data as mandated in the Affordable Care Act. However, it is not known what time point after death offers the most reliable responses.

**Objectives.** To examine the stability of bereaved family members' survey responses when administered three, six, and nine months after hospice patient death.

**Methods.** Bereaved family members from six geographically diverse hospices were interviewed three, six, and nine months after patient death. All respondents completed a core survey. Those whose family member died at home, in a freestanding inpatient unit, or in a nursing home also completed a site-specific module. Stability was based on top-box scoring of each item with kappa statistics, and multivariable regression models were used to assess directionality and predictors of change. To analyze the effects of grief, we assessed response stability among respondents at least one SD from the mean change in grief between three and six months.

**Results.** We had 1532 surveys (536 three-month surveys, 529 six-month surveys, and 467 nine-month surveys) returned by 643 respondents (average age 61.7 years, 17.4% black, and 50.5% a child respondent) about hospice decedents (55.3% females, average age 78.6 years, 57.0% noncancer, and 40.0% at home). The average kappa for core items between three and nine months was 0.54 (range 0.42–0.74), 0.58 (0.41–0.69) for home-specific items, and 0.54 (0.39–0.63) for nursing home. Even among individuals demonstrating large grief changes, core items demonstrated moderate to high stability over time.

**Conclusion.** Bereaved family member responses are stable between three and nine months after the death of the patient. *J Pain Symptom Manage* 2015;50:17–27. © 2015 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

## Key Words

Hospice, bereavement, grief, response stability, quality measurement

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## Introduction

The provision of hospice and palliative care services for patients at the end of life is growing.<sup>1</sup> In 2012, the National Hospice and Palliative Care Organization estimates that more than 1.5 million patients received services from hospice. Ensuring high quality of hospice care for the dying, therefore, is essential. Bereaved family interviews are a common and useful

way to gather information on hospice quality of care, as evidenced by their use in several influential studies to date.<sup>2–5</sup>

The Affordable Care Act<sup>6</sup> requires the Centers for Medicare & Medicaid Services (CMS) to publicly report hospice quality data. CMS has elected to use a bereaved family member survey as part of its Hospice Quality Reporting Program because of its several

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advantages over prospective interviews with hospice patients. First, the retrospective approach ensures that a similar time frame is compared, which is important given changes in utilization and symptoms closer to death. Second, prospectively identifying dying patients is difficult secondary to limitations of prognostication.<sup>7</sup> Third, many dying patients are unable to be interviewed in the last weeks of life, and there is an important concern with respondent burden when interviewing a person close to death. Among seriously ill, hospitalized persons enrolled in the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment, Wenger et al.<sup>8</sup> found that 40% of patients were unable to be interviewed. Those unable to be interviewed were sicker and closer to death. Key questions to consider are how bereavement impacts a family member's ratings and perceptions of the quality of care, and whether timing of survey administration will affect publicly reported hospice quality data.

Current research regarding stability of bereaved family member response is conflicting. Casarett et al.<sup>9</sup> found that respondents interviewed between two and six weeks after death were stable with regard to self-ratings of distress and satisfaction with care, whereas a study by Higginson et al.<sup>10</sup> raised concerns with the stability of bereaved respondent perceptions of symptoms and emotional state. Cartwright et al.<sup>11</sup> found no significant differences between bereaved family reports and direct patient reports in factual information, such as cause of death, place of death, and demographic information but found some small differences in responses concerning patients' symptoms, care received, and need for help. The National Hospice and Palliative Care Organization has recommended that the survey be administered between one and three months after death. This decision was based on the a priori logic that this period was far enough from death to not be burdensome but close enough that details of care could be recalled. The choice of the timing of survey administration must weigh tradeoffs between the impact of bereavement on the respondent's perceptions and the increased difficulty in locating respondents who move after the death of their loved one. An important policy question with the public reporting of hospice based on bereaved family interviews is whether the timing of the surveys impacts responses to quality-of-care questions.

The goal of the present study was to assess the stability of bereaved family member responses to a hospice quality survey and identify a time point most appropriate for administering such a survey. Because the stability of bereaved responses over time may be affected by changes in grief, a secondary goal of this study was

to assess whether changes in grief impact perceptions of quality of care at the end of life.

## Methods

### Sample

We recruited six hospice programs from diverse geographic regions of the country, including rural and urban locations and areas serving black and Hispanic populations. Survey administration was attempted from each participant at three, six, and nine months after the death of the hospice patient. All eligible respondents were sent a three-month survey and a six-month survey; only eligible respondents who had completed a three-month survey and/or a six-month survey were sent a survey at nine months. Potential respondents were mailed an information packet about the study and a toll-free phone number to opt out of the study. A self-administered survey also was included in the packet. Up to five follow-up calls at different times of the day were made to individuals who did not return their survey within two weeks. For those who chose to do so, we conducted a telephone-administered version of the survey. Participants enrolled in this study were the next of kin or close relatives or friends of a person who died while receiving hospice services at home, in a nursing home, or in a freestanding hospice inpatient unit (IPU). English and Spanish versions of the instrument were available to participants. All data collection was conducted through the Survey Center in the School of Public Health at Brown University.

### Measures

The revised Family Evaluation of Hospice Care (FEHC) comprises core items for all sites of care and three site-specific modules. Core and setting-specific items were based on review of the existing guidelines, input of an expert panel, and focus groups and cognitive-based interviews with bereaved family members. These items included survey questions from the original FEHC<sup>12,13</sup> survey and new items that were created in the following three modules: 1) a module that focused on the care of hospice patients in the nursing home, 2) a module that focused on the care of the hospice patient in the freestanding IP, and 3) a module that examined hospice's important role in educating and training the family member to provide hands-on care to the dying patient in the home setting. All items were scored based on whether the family member's or close friend's response indicated that there was an opportunity to improve the care received by the patient.

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