

Original Article

Family Perceptions of Quality of Hospice Care in the Nursing Home

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Abstract

Context. Nursing homes (NHs) are increasingly the site of hospice care. High quality of care is dependent on successful NH-hospice collaboration.

Objectives. To examine bereaved family members' perceptions of NH-hospice collaborations in terms of what they believe went well or could have been improved.

Methods. Focus groups were conducted with bereaved family members from five diverse geographic regions, and included participants from inner city and rural settings, with oversampling of African Americans.

Results. A total of 28 participants (14.8% African American, mean age 61.4 years) identified three major aspects of collaboration as important to care delivery. First, most (67.9%) voiced concerns with knowing who (NH or hospice) is responsible for which aspects of patient care. Second, nearly half (42.9%) stated concern about information coordination between the NH and hospice. Finally, 67.9% of the participants mentioned the need for hospice to advocate for high-quality care rather than their having to directly do so on behalf of their family members.

Conclusion. The important concerns raised by bereaved family members about NH-hospice collaboration have been incorporated into the revised Family Evaluation of Hospice Care, a post-death survey used to evaluate quality of hospice care. *J Pain Symptom Manage* 2014;48:1100–1107. *Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.*

Key Words

Hospice, nursing home, quality care, family perception

Introduction

Nursing homes (NHs) are an important site of death in the United States, with more than one of four adults dying in the NH setting.¹

Since the 1986 extension of the Medicare Hospice Benefit to NH residents, NHs are increasingly serving as the site of hospice care. From 2005 to 2009, the number of Medicare hospice beneficiaries in NHs grew by 40%.² By 2012,

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17.2% of all hospice patients died in the NH setting.³ Existing research recognizes problems with collaboration between the hospice and NH as a major barrier in delivering high-quality care for NH residents at the end of life.⁴⁻⁷

In its 2013 final rule-making for long-term care facilities, the Centers for Medicare and Medicaid Services (CMS) emphasized hospices' need to collaborate with NHs to ensure that the hospice patients receive the same high quality of care in NHs as in their personal homes.⁸ Given this CMS final rule, our goal is to measure the quality of NH-hospice collaboration by adding on to an existing instrument for measuring the quality of hospice care. The Family Evaluation of Hospice Care (FEHC) Survey is a National Quality Forum–endorsed instrument that most hospices now use on a voluntary basis to monitor their quality of care. As a first step to developing a new module, we conducted focus groups with a diverse population of bereaved family members to examine from their unique perspectives the successes and shortcomings in the care provided by hospices in the NH.

Methods

Focus groups are a useful method for collecting qualitative data on complex concepts, such as issues in the quality of end-of-life care. This qualitative method allows for solidifying of theoretical concepts with specific quotations from individual participants, while potentially allowing researchers to analyze interactions among group participants.^{9,10} Between December 2010 and May 2011, five focus groups were conducted with bereaved family members of patients who died with hospice in the NH; these sessions took place throughout the northeastern, southern, and southwestern parts of the U.S. Family members were first contacted between six and 12 months after the patients' deaths, through a letter describing the study's goals and terms of participation. They were then contacted via telephone approximately two weeks after receipt of the letter to screen for eligibility and determine interest in participating in a group discussion.

The focus group discussions were based on a moderator's guide designed to elicit family

members' perceptions of hospice care in NHs. Within this overall goal, a main focus of the moderator's guide was to explore the bereaved family members' observations of the coordination of care between NH and hospice. Focus group participants were prompted to tell their stories through open-ended questions such as:

- What were some good and bad experiences in the NH before hospice got involved?
- Once hospice got involved in the patient's care, what went well? What could have been improved?
- How well did the NH and hospice staff members interact with one another?
- Between the NH and hospice, how well was care coordinated? What could have been improved?

Each focus group discussion lasted approximately 90 minutes, after which each participant was compensated \$50 for his or her time. The discussions were moderated by the study's co-investigator (M. C.) and observed by the principal investigator (J. M. T.) and research assistant (C. W.), both of whom made independent notes of their observations. Focus group participants were informed that this study was part of the research team's ultimate goal of improving patient-centered and family-focused hospice care.

All focus group discussions were audiotaped and transcribed. The transcripts and notes from all sessions were analyzed to identify major themes of concerns that participants repeatedly voiced, citing both positive and negative experiences. The main goal of analysis was to identify those aspects of NH-hospice collaboration that participants seemed to believe most impacted quality of care for their deceased family member. Content analysis was conducted by J. M. T. and D. H. After review of the transcripts, J. M. T. outlined three major themes of concerns and discussed these themes with the team of co-authors; areas of disagreement were resolved through group discussion to reach consensus. After identification of the major themes, all transcripts were reviewed once more by D. H. to quantify the proportion of participants who brought up experiences or concerns corresponding to each category. This project was approved by the Institutional Review Board of Brown University.

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