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Original Study

Hospice Family Members' Perceptions of and Experiences With End-of-Life Care in the Nursing Home

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ABSTRACT

Objective: Even though more than 25% of Americans die in nursing homes, end-of-life care has consistently been found to be less than adequate in this setting. Even for those residents on hospice, end-of-life care has been found to be problematic. This study had 2 research questions; (1) How do family members of hospice nursing home residents differ in their anxiety, depression, quality of life, social networks, perceptions of pain medication, and health compared with family members of community dwelling hospice patients? (2) What are family members' perceptions of and experiences with end-of-life care in the nursing home setting?
Methods: This study is a secondary mixed methods analysis of interviews with family members of hospice nursing home residents and a comparative statistical analysis of standard outcome measures between family members of hospice patients in the nursing home and family members of hospice patients residing in the community.
Results: Outcome measures for family members of nursing home residents were compared (n = 176) with family members of community-dwelling hospice patients (n = 267). The family members of nursing home residents reported higher quality of life; however, levels of anxiety, depression, perceptions of pain medicine, and health were similar for hospice family members in the nursing home and in the community. Lending an understanding to the stress for hospice family members of nursing home residents, concerns were found with collaboration between the nursing home and the hospice, nursing home care that did not meet family expectations, communication problems, and resident care concerns including pain management. Some family members reported positive end-of-life care experiences in the nursing home setting.
Conclusion: These interviews identify a multitude of barriers to quality end-of-life care in the nursing home setting, and demonstrate that support for family members is an essential part of quality end-of-life care for residents. This study suggests that nursing homes should embrace the opportunity to demonstrate the value of family participation in the care-planning process.

In 2011, there were 15,671 nursing homes participating in Medicare and Medicaid programs. In that year, more than 1.4 million nursing home residents represented 2.9% of all Americans older than 65 and 10.7% of those older than 85 years.[1] More than one-quarter of older Americans die in a nursing home each year, yet research has repeatedly found the quality of end-of-life care in those facilities is less than adequate.[1,2] Although some residents improve their care with their Medicare hospice benefit,[3] considerable barriers remain for most nursing home residents needing palliative care.[2,4] Two systematic reviews of end-of-life care in nursing homes found challenges in identifying those facing end-of-life, pain management, collaboration with hospice providers, inappropriate hospitalization, lack of advance care planning, unmet family expectations, and communication problems among residents, family, and staff.[5,6]

Nearly 1 in 5 hospice patients resides in a nursing home.[7] To improve end-of-life care for those in the nursing home, rules for the

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Medicare hospice benefit were clarified in 1989, allowing residents in long-term care facilities access to their hospice benefits in this setting. Medicare regulation requires hospice programs to contract with individual nursing homes and provide all the services hospice would normally provide to its patients, including the coordination of care. However, while demonstrating benefit to residents,[8–11] hospice involvement in long-term care settings has not been without controversy and misunderstandings.[4,5,12–14]

The purpose of this study was to explore end-of-life care in the nursing home setting from the perspective of family members of residents who received hospice care. This study focused on 2 research questions: (1) How do family members of hospice nursing home residents differ in their anxiety, depression, quality of life, social networks, perceptions of pain medication, and health compared with family members of community-dwelling hospice patients? (2) What are family members' perceptions of and experiences with end-of-life care in the nursing home setting?

Our study was informed by the work of Saltz and Schaefer,[15] who developed a model for health care team collaboration that includes families. They identify 4 considerations for health care team collaboration inclusive of family: context, structure, process, and outcomes. The organizational **context** influences team **structure,** which in turn impacts team **processes**, which ultimately determine how teams evaluate **outcomes**. The model is described as nonlinear, with feedback loops between all components. For example, the culture and philosophy (context) of the nursing home may encourage or discourage family involvement in care. The (structure) composition, personality, education, background, and philosophy of the staff determine if there is a role on the team for family and whether family members are viewed as "lay" people (without detailed knowledge), or "specialists" (with a tremendous amount of knowledge regarding the patient). The involvement of family members in the problem-solving or decision-making (process) is typically very important. If not involved, incorrect assumptions can be made about the patient and family (such as their goals of care or treatment) and care can be affected. Finally, families influence outcomes by providing feedback about the care.[15] Family satisfaction can reinforce positive care, and dissatisfaction can lead to improvement or conflict. These 4 elements, context or philosophy of care, structure, process for family input, and family satisfaction (outcomes), are components of patient/family-centered care in any health care environment.

Methods

This study used secondary data that were collected during a clinical trial of a hospice family intervention funded by the National Institute of Nursing Research (R01NR011472). The trial facilitated hospice family involvement in care planning through Web conferencing. Family caregivers of hospice patients were randomized into either a usual care or an intervention group. The intervention group used Web-conferencing technology to participate in their plan of care meetings every 2 weeks, whereas the others continued to receive their usual hospice care and not participate in those meetings. Additional details of the trial, including the randomization process, have been published elsewhere.[16] The trial involved 4 clinically separate hospice programs from one Midwestern state from 2010 to 2014. The trial is registered with clinicaltrials.gov (NCT01211340) and approved by the University of Missouri Institutional Review Board and the administrative review bodies of the hospice programs.

Using a mixed-method approach, research question 1, which compares the outcome measures of nursing home and community-dwelling family members, was answered using outcome measurement data from all family members enrolled in the trial in either of the 2 settings. Research question 2, which explores only the perceptions of family members regarding end-of-life care in the nursing home setting, was answered with an analysis of interviews with family members of residents in that setting to lend insight into the potential meaning of the outcome measures. We used a retrospective secondary data analysis of the measures and interviews regardless of their intervention or control assignment. We compared measures with those of family members of community-dwelling hospice patients. We included the measures taken at enrollment and the last measure closest to death or discharge from hospice.

We collected family member demographics, as well as the patient Palliative Performance Score (PPS),[17] as documented by the hospice admission nurse. Clinical measures for family members of residents/patients in both groups included the Generalized Anxiety Disorder-7 (GAD-7), which assessed respondents' level of anxiety,[18] and the Patient Health Questionaire-9 (PHQ-9), which assessed their level of depression.[19] The Caregiver Quality of Life Index-Revised (CQLI-R) assessed a family member's perception of the quality of their life and has specific subscales related to emotional, financial, physical, and social quality of life.[20] We used the Lubben Social Network Scale-6 (LSNS-6) to measure the amount of social support available for an individual.[21] We also used the Caregiver Pain Medicine Questionnaire (CPMQ), a measure that assesses family members' perceptions of pain medication.[22] Finally, the Short Form-12 (SF-12) was used to assess general health, mental health, and physical health.[23] These measures were collected on study enrollment and every 2 weeks thereafter by telephone or e-mail.[16]

Data were entered into identical databases at each site and backed up to a central site weekly. Regular reports of potentially erroneous or missing data were generated to ensure high data quality. We compared characteristics of patients and their participating family members according to whether the patient lived in a nursing home or within the community. Categorical variables were compared using the χ^2 statistic, and the means of continuous variables were compared using *t*-tests.

Interviews were conducted with the family members of nursing home residents who enrolled in hospice by phone 2 weeks after the death or hospice discharge of the resident. No interviews were included with the community-dwelling family members. We used a semistructured interview instrument whose primary purpose was to understand the family members' experience with the clinical trial. As the interviews were transcribed, the rich descriptions of family experience in the nursing home led to this secondary analysis. Comments in the interviews reflect comments regarding the nursing home care while enrolled in hospice. Comments made regarding experience with hospice care (unrelated to the nursing home experience) were specifically excluded. Family members of patients who transitioned in or out of a nursing home while enrolled in the larger study were excluded.

All interviews were transcribed verbatim. Transcripts were coded and analyzed by 3 members of the research team (KW, AL, DPO). Initial codes were developed and discussed using the challenges of end-of-life care in the nursing home identified in the literature as well as the observations of the interventionists in the study. An Excel spreadsheet was created to assist tracking codes. Coders reviewed 30 transcripts together, discussing utterances and refining the coding categories. Twelve interviews were then independently coded and results compared; reliability was satisfactory (Kappa 0.83). The final 48 transcripts were coded independently by 2 of the coders.

Results

There were 166 nursing home residents and 246 community-dwelling hospice patients, with 176 and 267 participating family