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Original Study

Perceptions of Family Decision-makers of Nursing Home Residents With Advanced Dementia Regarding the Quality of Communication Around End-of-Life Care

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A B S T R A C T

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Objectives: (1) Compare family decision-makers' perceptions of quality of communication with nursing home (NH) staff (nurses and social workers) and clinicians (physicians and other advanced practitioners) for persons with advanced dementia; (2) determine the extent to which characteristics of NH residents and family decision-makers are associated with those perceptions.

Design: Secondary analysis of baseline data from a cluster randomized trial of the Goals of Care intervention.

Setting: Twenty-two NHs in North Carolina.

Participants: Family decision-makers of NH residents with advanced dementia (n = 302).

Measurements: During the baseline interviews, family decision-makers rated the quality of general communication and communication specific to end-of-life care using the Quality of Communication Questionnaire (QoC). QoC item scores ranged from 0 to 10, with higher scores indicating better quality of communication. Linear models were used to compare QoC by NH provider type, and to test for associations of QoC with resident and family characteristics.

Results: Family decision-makers rated the QoC with NH staff higher than NH clinicians, including average overall QoC scores (5.5 [1.7] vs 3.7 [3.0], $P < .001$), general communication subscale scores (8.4 [1.7] vs 5.6 [4.3], $P < .001$), and end-of-life communication subscale scores (3.0 [2.3] vs 2.0 [2.5], $P < .001$). Low scores reflected failure to communicate about many aspects of care, particularly end-of-life care. QoC scores were higher with later-stage dementia, but were not associated with the age, gender, race, relationship to the resident, or educational attainment of family decision-makers.

Conclusion: Although family decision-makers for persons with advanced dementia rated quality communication with NH staff higher than that with clinicians, they reported poor quality end-of-life communication for both staff and clinicians. Clinicians simply did not perform many communication behaviors that contribute to high-quality end-of-life communication. These omissions suggest opportunities to clarify and improve interdisciplinary roles in end-of-life communication for residents with advanced dementia.

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Improving communication about care of older adults with advanced dementia is a high priority, especially in nursing homes (NHs) where 70% of older Americans with dementia spend their final months of life.¹ The final phase of dementia is marked by worsening symptom distress and frequent medical complications, such as infections, injurious falls, and dehydration.² Thus, communication about goals of care and end-of-life treatment decisions is essential to promote the quality of life and quality of dying for this population.^{3–6} Routine communication among family decision-makers and NH staff (nurses and social workers) and NH clinicians (physicians and other advanced practitioners) may be helpful to prepare families for end-of-life treatment decisions and to guide treatment at the time of an acute illness.⁷

The interdisciplinary nature of communication in NHs is a fundamental challenge to delivering effective resident- and family-centered care.^{8–10} Families typically interact with nurses and social workers, but rarely meet with the physicians or other advanced practice clinicians who actually write orders about treatment.^{11–13} Prior studies suggest that NH staff and clinicians do not routinely communicate about goals of care with family decision-makers, leaving them uninformed about treatment options and unprepared for their roles as decision-makers.^{14–16} With the exception of the CASCADE study, which described limited family participation in end-of-life conversations for residents with dementia at the end of life,² prior studies have largely been retrospective assessments after death, rather than assessments of communication during the course of advanced dementia.

Addressing this gap in research, we conducted a secondary analysis of baseline data from the Goals of Care study, a clinical trial testing a decision aid intervention to improve goals of care communication for persons with advanced dementia.¹⁷ The purpose of this analysis was to describe current quality of communication between family decision-makers for persons with advanced dementia and NH staff and clinicians. Earlier studies suggest characteristics of residents (eg, dementia stage) and family decision-makers (eg, race) may influence end-of-life communication^{18–21}; thus, we examined the extent that characteristics of NH residents and decision-makers were associated with their perceived quality of communication. The specific objectives were (1) to describe family perceptions of quality of communication with NH staff and NH staff clinicians in general and specific to end-of-life care for persons with advanced dementia in NHs, and (2) to determine the extent to which the characteristics of residents and family decision-makers are associated with those perceptions.

Methods

The Original Study

The original Goals of Care study was a cluster randomized trial testing whether a video decision aid and structured care planning discussion improved the quality of communication, decision-making, and palliative care for NH residents with advanced dementia.¹⁷ The study examined the impact of the Goals of Care decision aid intervention over 9 months on the primary outcome of quality of communication by NH staff, and on secondary outcomes, such as palliative care domains in plans of care, completing Medical Orders for Scope of Treatment, and hospitalization. The study was conducted in 22 NHs in North Carolina. Trained research staff recruited dyads of older adults with advanced dementia and their family decision-makers between April 2012 and September 2014. Dyads were eligible if the NH resident was 65 years or older, diagnosed with severe to very advanced dementia confirmed by primary NH nurses as stage 5 to 7 on the Global Deterioration Scale,²² and if the family decision-maker spoke English. All data for this analysis were collected by

research staff in face-to-face interviews with the family decision-maker. Study procedures were approved by the University of North Carolina Institutional Review Board.

Data Source for the Secondary Analysis

We used baseline data collected by in-person interviews with family decision-makers for NH residents with advanced dementia. Baseline data included demographic characteristics of family decision-makers and the resident with advanced dementia, and family decision-makers' perceptions of the quality of communication with NH staff and with NH clinicians. Characteristics of NHs were obtained from a brief written survey completed by a member of the clinical leadership in each NH at the start of study enrollment.

Perceptions of Quality of Communication

Family decision-makers' perceptions of quality of communication in general and specific to end-of-life care were measured using the previously validated Quality of Communication Questionnaire (QoC).²³ This instrument measured 2 dimensions of the quality of communication: (1) general communication behaviors, defined as "how" health care professionals provide support and communicate with patients and families (6 items), and (2) end-of-life communication, defined as "what" professionals communicate about dying and care at the end of life (7 items).²³ Each item was scored from 0 ("worst") to 10 ("best"), and items do not specify a look-back time period. The QoC also included a response option of "didn't do" for each item, which was scored as 0 in analysis.²³ The overall QoC score and each subscale score was the sum of the item scores divided by the number of items. Because of the distinct roles in care and communication, family decision-makers were asked to give separate ratings of the quality of communication for NH staff (nurses and social workers) and NH clinicians (physicians, nurse practitioners, or physician assistants).

Statistical Analyses

Descriptive statistics (eg, means, standard deviations, frequencies) were used to summarize QoC scores and characteristics of family decision-makers. The normality assumption of the QoC scores was ensured by the Shapiro test. Scores for individual QoC items by NH staff and clinicians were described by calculating the percentage of family caregivers who chose the "didn't do" response for individual items. QoC scores with staff were compared with clinicians for the overall scale, and for general and end-of-life communication subscales. We tested the difference for statistical significance via a 2-sided *t*-test for a coefficient in the linear model using an indicator variable for the role (staff and clinician) in the NH. We also used a linear model to determine the extent that quality of communication was associated with (1) age, gender, race, stage 5 to 7 on the Global Deterioration Scale (GDS), NH length of stay of NH residents, and (2) characteristics of age, gender, race, relationship to the resident, or educational attainment of family decision-makers. All comparisons and associations were adjusted for the latent clustering effects of NH via adding a random intercept in the linear model. Analyses were implemented using SAS 9.3 (SAS Institute, Cary, NC). In analyses with single comparisons, a *P* value smaller than .05 was considered statistically significant; in analyses with multiple comparisons, to reduce the risk of Type I errors, differences were considered statistically significant when the *P* value was smaller than .025 (= .05/2).

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