Original Study

Representation in the Care Planning Process for Nursing Home Residents With Dementia

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ABSTRACT

Objectives: Federally mandated assessments of nursing home (NH) residents drive individualized care planning. Residents with cognitive impairment may not be able to meaningfully communicate their care needs and preferences during this process—a gap that may be partially addressed by involving surrogates. We describe the prevalence of family participation in the care planning process for long-stay NH residents with varying degrees of cognitive impairment.

Design: Retrospective study using administrative data made available as part of an ongoing pragmatic cluster randomized controlled trial.

Setting: A total of 292 NHs from 1 large for-profit NH system.

Participants: Long-stay NH residents in 2016.

Measurements: We identified all care planning assessments conducted in 2016 for long-stay NH residents. Cognitive functioning was defined using the Cognitive Function Scale. The Minimum Data Set was used to determine whether a resident, family member, and/or legal guardian participated in the assessment process. Certification and Survey Provider Enhance Reporting system data was used to identify facility-level correlates of family participation. Bivariate and multivariable hierarchical regression results are presented.

Results: The analytic sample included 18,552 long-stay NH residents. Family member/representative participation varied by degree of resident cognitive impairment; 8% of residents with no cognitive impairment had family or representative participation in care planning during 2016, compared with 26% of residents with severe impairment. NHs with more social worker had greater family participation in care planning. Available NH characteristics do not explain most of the variation in family participation between NHs (residual intraclass correlation = .57).

Conclusions: Only a minority of family members and surrogates participate in NH care planning, even for residents with severe cognitive impairment. The association between social work staffing and participation suggests family involvement may be a measure of quality improvement capacity. Our findings suggest a lack of voice for a vulnerable population that may have implications on the quality of care received at the end of life.

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Overall, resident participation in their own care planning assessments is high; over 80% of all NH residents are able to respond to assessment items screening for pain, cognition, and depression. However, NH residents with dementia were 40% less likely to be able to participate in their care planning assessments compared with cognitively intact NH residents. Involving family members in the care planning assessment process for NH residents with dementia may improve the quality of remaining life and the end-of-life care received by this vulnerable population.

The concept of involving family members or representatives in the NH care planning process is not new. In 1986, the Institute of Medicine’s “Improving the Quality of Care in Nursing Homes” report recommended NHs be required to notify a resident’s representative in the event of a care conference or other changes in the resident’s status (Recommendation 3–7D). The resulting Omnibus Budget Reconciliation Act of 1987 mandated written individualized care plans “prepared with the participation to the extent practicable of the resident or the resident’s family or legal representative” (HR 3545, SEC. 4201).

Yet, 30 years later, little is known about the prevalence of family and representative involvement in care planning for long-stay NH residents. The best available evidence comes from an Office of the Inspector General chart audit of 375 residents being prescribed atypical antipsychotics. The audit revealed that 91% of the time there was no evidence that the resident or the family member participated in the care planning process, and almost 60% of the time there was no documentation to explain why resident and family member participation was impractical.

To our knowledge, this report is the first of its size to consider family participation in the care planning process for long-stay NH residents with and without dementia. The objectives of this report were to (1) describe the prevalence of family participation in care planning for long-stay NH residents with varying degrees of cognitive impairment; and (2) identify other resident and NH characteristics associated with family participation in care planning.

Methods

We conducted a secondary analysis of data provided directly to researchers by a large, for-profit NH organization participating in PROVEN, a Pragmatic trial Of Video Education in Nursing homes. Details of this pragmatic, cluster-randomized trial have been published elsewhere. Briefly, the goal of the trial is to test a video intervention to improve advance care planning in NHs, particularly among long-stay residents with advanced dementia and other life limiting illness.

Sample

The sample for this study consisted of long-stay NH residents who had a quarterly or annual assessment in the last quarter of 2015 (October 1 through December 31, 2015), and at least 1 quarterly, annual or change in status assessment in 2016. To facilitate multilevel analyses, we further limited the analytic sample to NHs in which at least 25 residents met our criteria for prevalent long-stay residents.

Data

Long-stay NH residents in Centers for Medicare and Medicaid Services (CMS)-certified NHs are assessed at least once per quarter. The Resident Assessment Instrument is the standardized tool used to conduct these assessments. The data from these assessments is referred to as the Minimum Data Set (MDS). MDS data include information on resident preferences, ADL, diagnoses, cognition, and overall health status. MDS data were linked to NH-level data from LTCfocus (LTCfocus.org) and the Certification and Survey Provider Enhanced Reporting system (Medicare.gov).

Variables

Cognitive functioning

We used the Cognitive Function Scale (CFS), to classify long-stay residents’ cognitive functioning as cognitively intact, mildly impaired, moderately impaired, or severely impaired. The CFS is created using 2 measures: the Brief Interview for Mental Status (BIMS) and the Cognitive Performance Scale (CPS). Briefly, the BIMS is a resident screening tool with 3 cognitive tasks: immediate recall of 3 words, delayed recall of 3 words, and orientation to year, month, and day. The BIMS is not completed on residents who are “rarely or never understood.” The CFS uses the CPS to account for missing data on the BIMS. The CPS is based on several items available in the MDS that do not require resident feedback including staff members’ assessment of resident: short-term memory, cognitive skills for daily decision making, ability to make oneself understood, and eating dependence.

Participation in assessment

MDS, v 3.0, Section Q, Items Q0100A-C, ask the MDS assessor to record whether or not the resident, family member, or legal authorized representative participated in the assessment process (yes or no). There is also a place to indicate that no family members or legal representatives exist for the resident. The instructions for completing this item describe the importance of resident and family participation in assessment interviews and care planning meetings, described collectively as the assessment process. According to the Resident Assessment Instrument, participation should be assessed by reviewing the resident’s medical record; asking the resident, family member, or legal representative directly; and asking staff members who completed the assessment.

Other resident-level characteristics

Although we were primarily interested in family participation by degree of resident cognitive impairment, we explored several other resident-level characteristics that we hypothesized might be associated with family participation including: age (years); sex; marital status (currently married vs widowed, divorced, or never married); race (only black vs all other groups that were predominately white).
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