

Enhancing Life Quality for Residents with End-Stage Dementia and Families

Background and Significance

Caring for persons with advanced dementia in nursing homes is challenging for nursing home clinicians and devastating for families. The chronic, progressive cognitive and physical decline in end-stage dementia is compounded by numerous co-morbidities and an increasing frequency of acute events (e.g., pneumonia). Patients' families face the need to make treatment decisions regarding interventions such as artificial nutrition, CPR, and hospitalization often without adequate knowledge or support. There is no universal approach to care of the end-stage dementia patient. Some nursing home physicians prescribe and/or families demand aggressive care (diagnostic tests, antibiotics, intravenous therapy, feeding tubes) in advanced dementia, although much of the literature recommends avoiding medical interventions in this case. Advance directives may not be broached by staff or families until death is imminent. Other primary care teams are more likely to consider a palliative approach and/or referral to hospice. Defined as an interdisciplinary initiative that maximizes physical and psychosocial comfort for the dementia patient and his/her involved family, a palliative approach to care is driven by the goals of care for that particular patient. Only a small percentage of the many elders with advanced dementia receive palliative care to ease this final transition for themselves and their families. Although use of palliative care and hospice principles has long been encouraged for this vulnerable population, there is minimal empirical evidence of its profound potential for both patients and families. Families need education about the potential burdens and benefits of interventions, and the use of palliative care techniques. Documented evidence of the success of this model could lead to the development of best practice models for late stage dementia patients. Future research can build on this model with the development of mechanisms for family and staff support.

Methods

Study participants are family members of residents who meet study criteria. Elders who meet criteria are age 60+, with a diagnosis of dementia documented in the medical chart, and advanced dementia (MDS Cognitive Performance Score score = 4, 5 or 6; significant functional impairment). Exclusion criteria for elders includes residence in acute-care rehabilitation, cognitive impairment due to another cause (e.g., brain injury; end of life course may differ from those with a progressive dementia), and in hospice (can not randomize to the PCI or usual care control group).

This study is a 6-month, prospective, randomized trial of a structured palliative care intervention (PCI) versus a usual care control with social contact for families of residents with advanced dementia in a large skilled nursing facility. The PCI consists of formalized interactions between a trained palliative care team and involved families/friends of residents for the purpose of determining

goals of care, working to achieve those goals, and providing psychosocial support to the family. Usual care is that routinely provided to residents with advanced dementia which varies in terms of treatment offered and communication with family members including any efforts towards palliative care (unstructured). To control for the effect of greater attention to and greater interaction between staff (the Palliative Care Team; PCT) and families in the intervention group, a non-specific social contact component (regular, non-specific telephone contact with social work or nursing intern) is included in the usual care condition.

To monitor care over time, telephone interviews with family contacts are completed at three points (baseline, 3 & 6 months after baseline (or 4-6 weeks after a resident's death should that occur). Residents' medical interventions (emergency room visits, and hospitalizations), sentinel events (hip fractures, pneumonia), and advance directives (DNR, DNH) are extracted from medical records. Analyses will examine within-group change over time, and between group differences to determine whether or not the PCI group families have different outcomes than the usual care control group families.

Current Status

The project is in the baseline data collection phase.

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