ORS Grant

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Student (if applicable): Not applicable

Project Title: A Nursing Home Pragmatic Clinical Trial of APPROACHES (Aligning Patient Preferences: a Role Offering Alzheimer’s patient, Caregivers, and Healthcare providers Education and Support)

Funding Agency: NIH/NIA (R21/R33)

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Abstract A significant number of patients Alzheimer’s disease or related dementia diagnoses will be cared for in nursing homes near the end of life. Unfortunately, many of these patients experience unwanted and burdensome medical treatments, such as potentially avoidable hospitalizations, that negatively impact quality of life. Advance care planning (ACP) discussions with patients and family caregivers are important to explore goals in advance of a crisis and support informed, values-based decision-making. The ACP process helps ensure that preferences about treatments such as hospitalization are known, documented, and honored. Research indicates that ACP can reduce burdensome treatments and increase the likelihood that care will match documented preferences. Nursing homes are currently required by regulations to offer ACP to patients and families. However, there are no training requirements for nursing home staff and approaches to fulfilling this regulatory and ethical responsibility vary widely, resulting in inconsistent ACP. The “Aligning Patient Preferences – a Role Offering Alzheimer’s patients, Caregivers, and Healthcare providers Education and Support (APPROACHES)” trial will test the ACP Specialist Program. Existing nursing home staff members will be trained to enhance care and reduce unwanted, burdensome hospitalizations through improved ACP procedures, standardized staff education on ACP, and systematic ACP facilitation. The primary trial outcome is hospital transfers (admissions and emergency department visits) per 1000 person-days alive. Consistent with the spirit of a pragmatic trial, study outcomes rely on data already collected for quality improvement, clinical or billing purposes. In the 18 month R21 pilot phase, the aims are to: 1) Establish the trial’s organizational structure and processes; and 2) Pilot test the intervention in 4 nursing homes. In the R33 phase, a pragmatic cluster randomized clinical trial will be conducted in partnership with 3 nursing home corporations who operate a combined total of 206 diverse urban and rural facilities in 14 states. The aims of the 42 month R33 phase are to: 3) Evaluate the primary outcome of hospital transfers over 12 months among patients with dementia in intervention versus control nursing homes; and 4) Compare ACP documentation, measures of quality of care at the end of life, and patient and family satisfaction between the intervention versus control nursing homes. If successful, the ACP Specialist Program will be primed for rapid translation into nursing home practice to reduce unwanted, burdensome hospitalizations and improve quality of care for patients with dementia.