

Title: Improving Palliative Care Outcomes for Patients with Alzheimer’s Disease and Related Dementias and Family Caregivers

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Problem Statement: Alzheimer’s Disease and Related Dementias (ADRD) affect large numbers. Cognitive decline limits decision-making and compounds surrogate distress. Persons with ADRD and family caregivers struggle with unmet needs. Embedding Advance Care Planning (ACP) and burden assessment for Program for All-Inclusive Care of the Elderly (PACE) is an opportunity to expand services to improve palliative care (PC) outcomes while supporting community participants and caregivers.

Background: Database literature search spanned 2016-2021 in PubMed, Embase, and Google Scholar found that early and recurrent ACP with surrogates is key to delineating goals of care, preparing for inevitable complications, and culminated in timely access to palliative and hospice care.

Purpose: To determine the effect of a PC intervention for PACE participants with ADRD and caregivers on ACP documentation, hospice utilization, and caregiver satisfaction and feelings of support.

Methods: During January-March 2022, seven PACE participants and caregivers were scheduled for ACP with Zarit-12 burden survey during one-hour visits. Subsequently, caregiver satisfaction was measured utilizing combined quantitative (4-point Likert) and open-ended survey. A resource page was provided to participants. Data were content analyzed to determine if patient and caregiver needs were better met.

Findings: Of seven PACE participants, five were visited at home, two in adult family home (AFH); ACP was affirmed (N=5) and facilitated (N=2). Documentation referencing values and shared decisions was 100%. Caregivers were moderately burdened yet, believed that the ACP intervention was important (mean = 3.71). Qualitative reporting identified the experience as: “family oriented” and “honored in ways that reassured.” One death recorded on hospice in AFH within 6 months of admission.

Conclusion/Implications for Practice: Participants with ADRD and caregivers report benefit from ACP. Unmet needs may be better supported through expanding engagement with PC services set in PACE. Future directions may align with hybrid in-person and remote technologies integral to community-based care.