End- of Life Decision Making by Dementia Caregivers

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**Background:** Caregivers often feel unprepared to make treatment decisions for the dementia patient. Very little is known about factors that support preparation and engagement in treatment decisions in late-stage dementia, when these choices are required. Greater knowledge of dementia and its prognosis are factors that might help family decision-makers engage in advance care planning

**Objective:** To investigate whether family perceived prognosis, knowledge of dementia, and education level are associated with decision-making in advance care planning decisions for persons with late-stage dementia.

**Methods:** Participants were enrolled as dyads of patients and family decision-makers. Eligible patients had clinician-confirmed dementia staged 5-7 on the Global Deterioration and were hospitalized due to an acute illness. Family decision-makers participated in an in-person enrollment interview, with structured items to measure family caregiver’s perception of prognosis, knowledge of dementia, and their education level. The primary outcome was decision-making for advance care planning, operationalized as self-report of decisions on common treatments included in advance care planning: hospitalization, use of feeding tube, use of a central intravenous line, surgical procedures, ICU transfer, ventilator use, CPR use, treatment for pain, and treatment of emotional distress.

**Results:** 125 family decision-makers were approached about the study, and 57 (46%) enrolled. One-third of the decision makers believed that the dementia patient would be better or stay about the same, and two-thirds expected the patient’s health to worsen or even result in death. Family decision-makers generally decided for hospitalization (94%), ICU transfer (74%), treatment for pain (98%), and treatment for emotional distress (93%); they frequently decided against using a feeding tube (46%), a ventilator (68%), and CPR (58%). Reports of indecision were highest for feeding tube (28%). There was no significant correlation between summary scores for overall decisiveness or for the number of decisions against use of specific treatments and level of education, dementia knowledge, or assessment of patient prognosis, after adjusting correlations for the patient’s dementia stage.

**Conclusion:** Since prior knowledge of dementia and educational level at baseline do not seem to be a causal factor, this suggests that it is the physician’s responsibility to discuss dementia and end-of-life care to the family decision-maker, and to explore not only their understanding of information but the factors they consider important in advance care planning decisions.