

NAPCRG 52nd Annual Meeting — Abstracts of Completed Research 2024.

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Title

Advance Care Planning: comparison of views of people living with dementia and their caregivers

Priority 1 (Research Category)

Palliative and end-of-life care

Presenters

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Abstract

Context: Advance Care Planning (ACP) with people living with dementia is complicated by the decline in capacity and varying course as the condition progresses. Objective: To explore and compare the perspectives of people living with dementia and their family caregivers regarding ACP.

Study Design and Analysis: Cross-sectional study with semi-structured individual interviews. Transcribed interview recordings were analyzed with a qualitative thematic approach using Atlas.ti (2024) software. Setting: In-person or virtual interviews.

Population studied: Six dyads of people with mild dementia and their family caregivers in Missouri, US.

Intervention: Participants were prompted by animated video vignettes illustrating two approaches to ACP: concrete treatment orders or important goals. Outcome measures: Acceptability of ACP as described by inductive qualitative thematic analysis, as well as preference for the two ACP approaches.

Results: Generally, both groups viewed ACP as acceptable for people with dementia and had no preference between the approaches. Two themes were identified: (1) Avoiding Burden and suffering

and (2) Roles and Responsibilities. Members of both groups emphasized the importance of minimizing the person with dementia's future suffering and decision-making burden for family members. One person with dementia and several caregivers mentioned the potential for family conflict both in the process of ACP discussions and at a future time when decisions would need to be implemented. Regarding theme 2, changes in the capacity of people with dementia as the condition progresses and the importance of clinicians facilitating ACP conversations were salient concerns. Caregivers noted the importance of using clinicians' knowledge of what might be expected with disease progression. However, people with dementia and caregivers wanted to be sure there was a trusting relationship and were unsure if physicians would be available due to their busyness. Half of the people with dementia avoided discussing ACP as it applied to them; some denied their condition, and some appeared to see no benefit.

Conclusions: Some people with dementia and particularly their caregivers recognize the benefits of ACP in limiting suffering for the person with dementia and the decisional burden for caregivers. Participants found both approaches to ACP acceptable; however, roles of people with dementia, family caregivers, and clinicians need to be clarified and negotiated.

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