

How Do Surrogates Make Treatment Decisions for Patients with Dementia:  
An Experimental Survey Study

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**Abstract**

Despite the growing need for surrogate decision-making for older adults, little is known about how surrogates make decisions and whether advance directives would change decision-making. We designed an experimental, vignette-based survey that cross-randomized cognitive impairment, gender, the relationship between surrogate and patient, presence and characteristics of advance care planning, framing of the decision, the patient doctor's recommendation, and prevailing social norms at the patient's hospital. We administered the survey to three distinct cohorts from the nationally representative Ipsos Knowledge Panel, each comprising approximately 2,000 US adults aged 18 and above. The first group was a random selection, the second consisted of caregivers, and the third included individuals with chronic illnesses. We have five key results: 1- Respondents were much less likely to recommend life-sustaining treatments for patients with dementia; 2- Respondents frequently ignore patient preferences for life-extending treatment, especially when the patient has dementia, and were more likely to choose unwanted life-extending treatments for patients without dementia; 3- The "dementia penalty" was somewhat larger among respondents who are chronically ill and, especially, respondents who are caregivers for another adult; 4- Both doctors' recommendations and prevailing social norms influence the respondents' choices; and 5- Respondents were more likely to choose treatments that matched their own preferences, especially when there was uncertainty about the patient's wishes. These findings underscore the need for improved communication and decision-making processes for patients with cognitive impairment and highlight the importance of choosing a surrogate decision-maker with similar treatment preferences.

**Keywords:** Cognitive impairment, Surrogate decision-making, Advance care planning, End-of-life care, Preferences.

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